DOCUMENT RESUME

ED 307 564 CG 021 734

AUTHOR Marcec, Andrew
TITLE The Alzheimer Disease Afflicted: Understanding the Disease and the Resident Instructors Guide and Teaching Materials.
INSTITUTION Illinois State Dept. of Public Aid, Springfield.
PUB DATE 87
NOTE 84p.; One of a series of reports issued under the the heading: "1987 Long Term Care Research and Demonstration Projects. Final Reports. New Horizons in Long Term Care." (see CG 021 733, 735).
PUB TYPE Guides - Classroom Use - Guides (For Teachers) (052)

EDRS PRICE MF01/PC04 Plus Postage.
DESCRIPTORS *Alzheimers Disease; *Caregivers; Death; Family (Sociological Unit); Intervention; *Training Methods

ABSTRACT

The learning modules contained in this document are designed to permit instructors in many settings to deliver high quality training to caregivers of Alzheimers' disease patients. Instructors can prepare by reviewing the Instructor's Guide which outlines the behavioral objectives each learner will be expected to achieve to complete the module as proposed. In this manual, the instructor is given the primary learning resources to be used in preparation for teaching. There are details of specific interventions which the caregiver would use in the administration of care to the resident. Narrative material is provided as a supplement to journal articles, books, and other primary learning materials. Definitive information which could be presented in a lecture format and would assure that all of the learner objectives would be covered in the lecture is included. An exercise is provided with each module which the learner may complete alone or in a group with other participants. Specific topics covered include defining Alzheimer's disease, communications, care strategies, family burdens, sensory loss, and dying and bereavement. (Author/ABL)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED307564

THE ALZHEIMER DISEASE AFFLICTED: UNDERSTANDING THE DISEASE AND THE RESIDENT INSTRUCTORS GUIDE AND TEACHING MATERIALS

by
Andrew Marcec

Division of Continuing Education
Southern Illinois university
Carbondale, Illinois

Andrew Marcec, Project Director
Helen Porter, Co-project Director

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
☑ This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY
Jean Merritt
TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

CG 021734

Illinois Department of Public Aid
Long Term Care Research and Demonstrations Projects
Jo Ann Day, Ph.D., Project Manager

The statements contained in this report are solely those of the authors and do not necessarily reflect the views of policies of the Illinois Department of Public Aid. The authors assume responsibility for the accuracy and completeness of the information contained in this report.

BEST COPY AVAILABLE

Illinois Department of Public Aid

Edward T. Duffy, Director

1987

LONG TERM CARE RESEARCH AND DEMONSTRATION PROJECTS

FINAL REPORTS

CG 021734

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

☑ This document has been reproduced as received from the person or organization originating it.

☐ Minor changes have been made to improve reproduction quality.

• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY

Joan Merritt

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

NEW HORIZONS IN LONG TERM CARE

Edward T. Duffy
Director

Illinois Department of Public Aid

Jesse B. Harris Building
100 S. Grand Avenue East
Springfield, Illinois 62762

Funds for collaborative research in long term care were appropriated in the Department of Public Aid's budget in Fiscal Years 1986 and 1987 to find new ways to treat long term care patients in Illinois nursing homes. The $2.5 million appropriation over the two years enabled the State, academic institutions, and providers of long term care to pool their talents for the first time. In all, there were 17 projects funded in Fiscal Year 1986 and 14 projects funded in Fiscal Year 1987, the final year of the Long Term Care Research and Demonstrations projects. The attached document is the final report from one of the 1987 projects.

The Department of Public Aid expects the ideas generated by these projects to be put into reality. There are, in fact, training programs already being disseminated as a result of the research.

This report is one of a series of reports that comprise the long term care projects funded during 1987. Copies of the other reports are available from the Department of Public Aid by writing to Jo Ann Day, Ph.D., Long Term Care Research and Demonstration Project Director, Office for Employment and Social Services.

Sincerely,

Edward T. Duffy
enc.

ETD:JD:gt

TABLE OF CONTENTS

USING THE MATERIALS	PG.1
"WHAT IS ALZHEIMER DISEASE ?"	PG.2
COMMUNICATIONS	PG.14
CARE STATAGIES	PG.31
FAMILY BURDENS	PG.42
SENSORY LOSS	PG.56
DYING AND BEREAVEMENT	PG.69

USING THE MATERIALS

The learning modules contained herein are designed to permit instructors in many settings to deliver high quality training to caregivers. Instructors can prepare by reviewing the Instructor's Guide. The Instructor's Guide outlines the behavioral objectives each learner will be expected to achieve to complete the module as proposed. In this manual, the instructor is given the primary learning resources to be used in preparation for teaching. Detailed here are specific interventions which the caregiver would use in the administration of care to the resident.

The narrative material is to be used by the instructor as a supplement to the journal articles, books and other primary learning resources. The narrative contains definitive information which could be presented in a lecture format and would assure that all of the learner objectives would be covered in the lecture.

The Exercise with each module is administered at the conclusion of the didactic presentation. The learner may complete the exercise working alone, or, in a group with other participants.

Each module is designed for a ninety minute presentation.

INSTRUCTOR'S GUIDE FOR "WHAT IS ALZHEIMER'S DISEASE"?

ESTIMATED WORK TIME: 90 minutes

DOMAIN: Neurological change

OBJECTIVES:

The participant will be able to:

1) Describe the attributes of Alzheimer's Disease.
2) Name the three phases of Alzheimer's Disease.
3) List symptoms associated with each phase.
4) Describe the nursing interventions with each phase.

EVALUATION CRITERIA:

Without error answer all questions in the exercise.

LEARNING RESOURCES:

Primary

1. Study Guide

2. Dahl, David S. "Diagnosis of Alzheimer's Disease," Postgraduate Medicine, Diagnosis, Vol. 73 no. 4, April, 1983, pp. 217-221.

3. Redder, Marie "Nursing Update on Alzheimer's Disease," Journal of Neurosurgical Nursing, Vol. 17 no. 3, June, 1985, pp. 190-200.

4. Schmudt, G. "Mechanisms and Possible Causes of Alzheimer's Disease," Postgraduate Medicine, Mechanisms and Causes, Vol. 73 no. 4, April, 1983, pp. 206-212.

5. Cohen, D., Kennedy, G., and Eisdorfer, C. "Phases of Change in the Patient with Alzheimer's Dementia: A Conceptual Dimension for Defining Health Case Management," Journal of the American Geriatrics Society, Vol. 32 no. 1, January, 1984, pp. 11-15.

6. Angel, R.W. "Understanding and Diagnosing Senile Dementia," Geriatrics, August, 1977, pp. 47-49.

7. Kellett, J.M. "Education in Dementia for the Caring Professions," Danish Medical Bulletin, Vol. 32 no. 1, February, 1985, pp. 67-70.

8. Mace, Nancy L., and Rabins, Peter V. The 36 Hour Day (John Hopkins University Press Baltimore).

9. Gwyther, Lisa P. Care of Alzheimer's Patients: A Manual for Nursing Home Staff (American Healthcare Association, Washington D.C.).

KEY WORDS

Dementia
Depression
Neurofibrillary tangles
Aluminum toxicity
Biopsy

INSTRUCTIONAL STRATEGY

GAIN ATTENTION

Alzheimer's disease is the fourth leading killer of people over 75, and these people are the fastest growing population group in our country. What does this mean to you the caregiver of an Alzheimer's (or AD) patient? One in three people will face coping with memory loss in a parent, older relative, or brother or sister. Most people with these memory problems are living at home alone or with their families, and not under strict medical or nursing supervision. Studies have shown that memory problems are the most difficult for families to manage.

INFORM LEARNER OF OBJECTIVE

The purpose of this unit of instruction is to teach you to recognize what Alzheimer's disease is according to its characteristics -- how it is different from other forms of dementia.

STIMULATE RECALL OF PREREQUISITES

People generally have thought that AD is a normal process of aging, one of those unfortunate things that happens to some older people. But people are beginning to realize that AD is not a mental illness, although the behavior often looks similar to that of patients with psychiatric (mental) problems. As you will see, AD is not the result of a lazy or retarded mind, an unstimulating environment, too much family conflict or family neglect (although all these conditions can make the disease worse). Wealth,

education, race, or healthy vigorous lifestyles don't protect anyone from getting AD.

PROVIDE LEARNING GUIDANCE

Definition

AD is a severe progressive and irreversible loss of memory and thinking ability in previously healthy middle aged or older persons. AD was identified and described by Dr. Alios Alzheimer in 1907.

Example

Let me give you an example of how a person inflicted with AD might behave. If an item like keys is lost, the AD resident does not know how to retrace her steps. She may not recall the last time she had her keys or may make-up a story to explain how the keys were lost.

Non-example

Here's an example of something that might be confused with AD. Pneumonia is an infection of the respiratory system. When combined with a brain which is loosing its reserve capacity, like that of any older person, pneumonia can interfere with a person's lifestyle. The side effects of an infection like pneumonia can make a person inattentive, unable to concentrate, and apathetic -- the results can resemble dementia.

Elaboration

The term AD is generally used to refer to a type of dementia. Dementia refers to a generalized cognitive (the ability to think) and intellectual impairment. The term dementia has often been used generally in reference to elderly people with any prominent mental defect.

[Display diagram of dementia 'tree' on overhead]

There are primary and secondary types of dementia. Primary dementias include diseases which primarily affect the brain and produce dementia through direct affects on brain tissue. The brain is the first organ affected. A direct examination of the brain tissue is required to determine what the disease is. This is usually obtained by an autopsy. Primary dementias such as AD are progressive illnesses -- the symptoms appear gradually.

Secondary dementias are associated with diseases which do not attack the brain directly. The symptoms of secondary dementia are caused by drugs, toxins, or diseases of organs other than the brain. They seriously interfer with the brains' ability to function. Secondary dementias usually happen suddenly, as with pneumonia example.

AD is a dementia of the primary type. It is the most common dementing illness. There is much that scientists don't know about AD, but there are a few well-accepted facts that are attributed to the disease.

[Display "Attributes" transparency on overhead and point to each attribute as it is discussed.]

Changes in the brain. First, let me talk about changes in the brain. Sometime during the course of AD, the nerve cells in the part of the brain that controls memory, thinking, and judgment are damaged. This interrupts the passage of messages between cells. Also, the thinking center (the cortex) of the brain shrinks (or becomes 'atrophic'). This shrinking of the brain makes for less surface area in the brain. The amount of surface area in the brain plays a part in how well a person can think and function. These are cognitive skills. During this process the nerve cells of the brain also develop specific changes -- they form something called tangles, "neurofibrillary tangles", and "plaques". These tangles and plaques are the hallmark of the disease as seen after death from an autopsy.

The nerve cells which are being destroyed in AD are the working components of the brain, the parts of the brain which control cognitive functions. From the nerve cells come the commands which set our muscles into motion. They contain our memories, receive the sights and sounds of our surroundings, and produce our emotions. Nerve tissue affected by tangels or plaques looks dead. A brain containing many of these destroyed nerve cells is not functioning well enough to interpret life in all of its richness.

Causes of AD. What causes AD? There is very little that we know about what causes AD, who gets it, and why. We know that it is not caused by hardening of the arteries or blood vessel disease. Most victims of AD have normal blood vessels leading to the brain. The reason blood vessels have been suspected is because a reduced blood supply to the brain can cause confusion.

We are also pretty sure that AD is not a sign of emotional or moral weakness since many fine, strong, productive people still get it. [Use example of your own.]

AD is not just the result of poisons in the environment, or too little blood or oxygen getting to the brain, or alcoholism, or malnutrition.

Some people believe that there are increased amounts of aluminum (which sometimes acts as a poison) in the brains of persons who die with AD, but no one is sure if that's the cause or just an effect of the disease. High aluminum levels have been found in both those people who died as a result of AD and in those who have died for other reasons. In some people who have been found to have had AD through an autopsy have not had any aluminum in their brains.

Chronic abuse of alcohol and/or malnutrition causes a different kind of memory impairing (or dementing) illness.

All this means is that we can't treat AD by feeding people better, restricting alcohol intake, or by giving them medicines to increase blood-flow or oxygen to the brain.

It has been thought that AD could be the result of a slow-growing virus, or an immune problem. But the most reliable current theory is that a specific neurotransmitter is lacking in patients with AD, which causes messages not to pass between nerve cells. Most of the recent experimental treatments have been attempts to replace this missing neurotransmitter or keep it from breaking down.

Age. The next attribute is age. Forgetfulness is part of the normal aging process and usually begins in early middle age. And, it is common for all of us to become more forgetful if we're depressed, grieving, overworked, or running in a million directions at once. Most people have had some experience losing their keys, their glasses, or their car in a parking lot. And we all forget names or occassional appointments, especially more as we age. But this is normal forgetfulness. People with AD not only forget things and events, but they have no clues that could help them to remember. They often makeup stories to explain things or actions. They not only forget past events, but they also forget entire recent experiences as well as things that happened just minutes before. [Teacher may inquire at this point if participants have an experience of their own they can share with the group].

AD patients can not retain spoken reminders. They may repeat the same question several times in an hour to the same person.

Heredity. Heredity is another attribute. There is a slightly increased risk that children, brothers, and sisters of patients with AD will get it, but most cases of AD are the only one in the family. Some patients who get AD in middle age have a "familial" type -- more than one case in the family. It

should be kept in mind that, at this time, the only way AD can be positively diagnosed is after death from an autopsy.

Diagnosis. The next attribute deals with diagnosis of AD. There is no single test for AD. AD is diagnosed by ruling out all other curable or incurable causes of memory loss. A positive diagnosis of AD can be made only by studying a small piece of brain tissue from an autopsy. Families should be encouraged to ask for an autopsy as a contribution to learning more about the genetics of this tragic disease. An interesting statistic is that thirty percent of autopsies on presumed AD patients turn up a different diagnosis.

It is essential that the family has the AD patient go through a thorough evaluation when the problem becomes noticeable. A clinical diagnosis can be made by doctors trained in various testing procedures.

[Show transparency of "Stages of Symptom Progression i Alzheimer's Disease" chart].

Stages of symptoms -- progression in AD. Another attribute relates to the stages of AD. There are three stages that AD patients go through. These are not distinct phases, they can overlap. The three stages are: forgetfulness, confusional, and the dementia or terminal phase.

In the first phase, which can last from two to four years, the signs and symptoms may be so subtle that the person with the disease may not be aware of them. This is the forgetfulness phase. The individual with AD will have difficulty in recalling familiar names of places and objects. Memory loss may be concealed by the person for a long time. The individual is still able to function in social and employment situations, but the recent memory loss does begin to affect job performance some.

Issues to be faced by family members at this time include denial of signs and symptoms by the patient (and non-primary caregivers), "cover up" behavior, and fear.

The second or confusional phase generally extends over may years (two to ten years). It begins at the point where cognitive deficit becomes obvious during a detailed clinical interview. Individuals have difficulty functioning well in demanding employment or social situations. They may not recall their clients' or students' names. They may be unable to find valuable objects, and may become lost when traveling to a familiar location. These are all examples of cognitive loss. Other characteristic signs and symptoms of this phase include a tendency to wander off and repetitive movements such as tapping, lip-licking, chewing, folding hands, or touching of the head.

During this second phase, the family must keep a close eye out and be protective of the AD family member. The family can become very stressed as they struggle and seek to balance their jobs with their caregiver role. The family may experience grief as they care for a person who no longer seems like the person they once knew. Some AD afflicted persons come to nursing homes in later stages of this phase.

The final dementia, or terminal, phase can be defined as beginning at the point at which, left on their own, patients can no longer survive. Difficulties in functioning and carrying out the basic daily activities are the hallmarks of this phase. AD patients can no longer recognize family or themselves in the mirror. They can't communicate with words. They lose weight even with a good diet. They may put everything in their mouth or touch everything. AD patients at this stage may have difficulty with seizures, swallowing, and skin infections. The AD victim usually dies from some other disease or illness because AD has weakened the body.

The family at this point faces the issue of institutional placement of the AD family member, and the guilt which is often involved with that placement. Families have to face the issue of identifying their losses and gains with institutional care. Families endure considerable personal and economic sacrifices to care for relatives with AD.

No cure. The last attribute we're going to talk about today is that there is no cure. People diagnosed with AD may live from two to twenty years after the onset of memory loss symptoms. AD shortens one's expected life span, but given safe environments, few demands, and good medical attention, many patients survive for many years at home or in a nursing home. Most symptoms of AD patients can not be prevented by good care or by the patient's previously "strong" personality or constitution. But by providing the AD patient with good care they will be happier.

There is no definite care or treatment for AD; however, the symptoms associated with AD can be managed.

What is Alzheimer's Disease?

Please answer the following questions. There might be more than one correct answer to each question. Circle all the correct answers.

1. AD is a severe progressive loss of memory and thinking ability that occurs in:

   a) People over 65 only.
   b) Middle-aged people only.
   c) In some cases, children of AD patients.
   d) Previously healthy middle-age or people.

2. While there is much that scientists don't know about AD, there are a few well-accepted facts:

   a) AD is caused by hardening of the arteries.
   b) AD is a brain disease.
   c) AD is a result of the normal aging process.
   d) No one is sure what causes AD, and as a result, no prevention or cure exists.

3. We don't know how to treat AD because,

   a) we can not diagnose AD positively until after death.
   b) we do not know exactly what causes it.
   c) chronic abuse of alcohol and/or mulnutrition has already impaired greatly the memory of the AD patient's brain at the point of the diagnosis, and it's too late for any kind of treatment.
   d) even many fine, strong, productive, and emotionally stable people still get AD.

4. It is common for all of us to be more forgetful when we are depressed, grieving, overworked or running in a million directions. In which ways does normal forgetfulness differ from AD?

   a) A normal person can use clues to help him/her remember things, whereas an AD patient can not.
   b) A normal person can not forget names and/or occasional appointments.
   c) A normal person does not lose his/her keys, glasses, or his/her car in a parking lot.
   d) A normal person would not repeat the same question several times in one hour to the same person.

5. The second phase of AD:

   a) is called the "confusional" stage.
   b) lasts for 6 months or less.
   c) affects the mood and sleep patterns of the afflicted person.
   d) makes it difficult for afflicted persons to deal with demanding work or social situations.

6. The terminal or dementia phase of AD:

   a) lasts from one to three years.
   b) begins when the resident can no longer survive on their own.
   c) is a sad phase, whereas the AD patients can no longer recognize family or self in mirror.
   d) affects patients greatly, but they can still control bowel, and bladder.

7. The best treatment for AD patients is to:

   a) feed them a good diet.
   b) restrict alcohol intake.
   c) provide them with mentally stimulating activities.
   d) give them medicine to increase the flow of blood or oxygen to the brain.
   e) There is no treatment that helps successfully.

8. What are the changes that happen in an AD patient's brain?

   a) The nerve cells get damaged.
   b) Thinking process, and memory function are interrupted.
   c) Formation of tangles and plaques affect the person's normal functioning.
   d) The nerve cells being destroyed have nothing to do with the passage of message of between cells.

9. In the first stage (the forgetfulness phase) of AD, which lasts two to four years, the afflicted person:

   a) can still function in social roles and employment roles.
   b) could never drive a care.
   c) may try to conceal their memory problem.
   d) can still remember names of familiar places and objects without any difficulty.

10. Why do families have to endure considerable personal and economic sacrifices to care for relative with AD?

    a) Care giving is very costly.
    b) Institutional placement can bring the family feelings of guilt.
    c) Home-care can make the family experience a lot of grief as the person who they once knew can no longer function and recognize them.
    d) Families feel that they are only wasting their time, money, and energy.

INSTRUCTOR'S GUIDE FOR COMMUNICATION EXERCISE

ESTIMATED TIME: 90 minutes

DOMAIN: Cognitive functioning

OBJECTIVES: The participant will be able to:

1. Demonstrate effective listening skills by use of paraphrase, repeating and restatement.
2. Compose short specific, simple sentences using familiar words.
3. Use proxemics, distancing and touch, and eye contact.
4. Demonstrate effective speech style with rate, diction and volume.
5. Demonstrate non-verbal skills of facial motion, torso position, upper extremity gestures, etc.
6. List other general guidelines or hints of effective communication.
7. Give examples of hidden messages and meaning.

EVALUATION CRITERIA

Without error complete the questions in the Communication Exercise.

LEARNING RESOURCES

Primary

1. Mace, Nancy L., and Rabins, Peter V. The 36 Hour Day (John Hopkins University Press Baltimore).
2. Gwyther, Lisa P. Care of Alzheimer's Patients: A Manual for Nursing Home Staff (American Healthcare Association, Washington D.C.).
3. Beam, Marlene I: Helping Families Survive. American Journal of Nursing 84(2):228-232, 1984.
4. Guidelines for Nurse/Patient Communication in Dementia. Journal of Gerontological Nursing.
5. Learning How to Communicate Benefits Patients, Caregivers. The Arizona Daily Star.

KEY WORDS

Paraphrase	non-verbal
Restate	rate
Proxemics	diction

COMMUNICATION STUDY GUIDE

NURSING DIAGNOSIS

Impaired communication. Usually caused by gradual loss of cortical areas of the brain which control memory, language and motor functions controlling speech patterns.

Symptoms: Resident shows strong nonlistening behaviors; may use verbal abuse with family or caregiver; in severe cases, all verbal abilities are lost and speaks by grunting.

NURSING INTERVENTIONS

--Approach resident unhurriedly, slowly
--Use slow clear and distinct speech,and wait for patient to respond
--Reassure verbally and by touch
--Ask one simple question at a time. If repeated, ask it exactly the same way
--Maintain calm body language. Do not appear impatient or annoyed
--Use signals other than words. Point, touch, or hand resident objects
--Use short words and short simple sentences
--Lower pitch (or tone) of voice. Do not speak loudly
--Ask resident to do one task at a time
--Carefully assess the resident's body language to determine pain or discomfort when resident is no longer able to talk or verbalize

In-service Communication

When using in-service communication it is important to remember that there is no one procedure for all the residents. What works with one resident may not work with another. Decisions on how to handle certain situations must be made according to the individual. However, there are some general in-service communication skills which are applicable when dealing with most residents. Following are some of these skills which were discussed at the last in-service communication meeting.

Non-verbal Communication

Touch is important in that it communicates concepts, feelings, thoughts, and warmth through the senses. If a staff member is frustrated it is noticeable by the way they touch the resident. For example, a staff member is pushing and shoving instead of being gentle with the resident. The resident with Alzheimer's can not comprehend such behavior due the fact that the disease attacks the brains ability to deal with such concepts. The resident in turn may interpret this as meaning that they have done something wrong. It is alright to get angry or frustrated but it is important not to react according to your emotions.

The question was asked; "Why some residents respond negatively to touch?" "And how do you communicate concepts, feelings, and thoughts non-verbally without touch?" One suggestion is to find out if there are certain areas of the body which the resident considers to be "taboo". Also, when appropriate the staff member might ask permission to touch the resident. For example, the staff member could ask if it would be alright to hold their hand as they walked down the hall. If they absolutely will not allow the staff member to touch them something like expressions are helpful in helping to communicate concepts, feelings, and thoughts.

Communicating Understanding: When communicating understanding there are five basic points which should be remembered:

1. Always approach the resident from the front.
2. Call them by name (find out exactly what they like to called).
3. Use eye to eye contact as much as possible.
4. Get on their level which will help keep their attention.
5. Lean forward when speaking to them.

These five points will help assure the resident that you are not a threatening force.

The previous five points are also essential in the practice of good communication. Additionally, it is important to make sure the resident can hear you. When speaking always use a calm manner, and speak slowly and distinctly. Your tone of voice should always be gentle. Remember to use simple words and short sentences. If they are not understanding try rephrasing the sentence and use more specific statements. A good example would be to say, "Do you want your sweater?", instead of just saying, "Do you want this?" The latter statement is far too vague for the resident to comprehend.

Don't argue with the resident and keep repeating things over and over. For example, if a resident were to say,"Art has not passed away.",you could respond, "I'm sorry Art has passed away. Does that make you feel lonely.?"

Avoid harsh and direct orders and try to phrase your sentences as questions. Avoid using sentences in the negative form. For example, "Don't sit in that chair", would not be the appropriate way to speak to the resident. These things are important to remember when dealing with such things as the simple communication of daily living, which is essential to them feeling as though they're still human beings. By doing this you are helping to improve their "quality of life". State instructions step by step. Don't take for granted that the residents remember functions which you consider simple, for example eating. Break down tasks to one thing at a time. Don't just say, "Sit in the chair", but go through the motions with the residents as demonstrated in the wheel chair exercise.

Attending: Attending involves cognitively and physically concentrating on one resident at a time. The staff member's heart, soul, and head should go into providing for the resident. The staff should always deal with the residents in terms of improving their daily functioning. You should not rush with the residents because they can not cope with this behavior and they do not know how to react. They can not interpret what it means. "Does it mean I should rush? I'm doing something wrong?" Often they do not remember how to rush. They can't remember how to do certain activities we take for granted. The staff member should be careful and make sure that, while attending, the resident does not get attached to them and refuse to react to anyone except them. An important part of attending is getting the resident to react for themselves.

Empathy: Empathy is saying that you can understand and can put yourself in their shoes. Staff members should empathize with the residents and not sympathize. Sympathy can be patronizing and negative in that it has a tendency to pass judgement. Be sure to verbalize you empathy and let them know you feel with them.

Respect: You can not have any of the four previous skills without respect. Respect can be shown in many ways. One way is to find out what they like to be called and always call them by that name. Another way is to treat them like an adult when you deal with them.

Accepting: Accepting deals with accepting the resident the way they are. It is helpful to know something about the resident's past, which can help you understand them.

Self-Revealing: Be honest with the resident and tell them where you are at. This does not mean bringing your problems to work and dumping on the resident. However, you can say something to the affect that things aren't going well at home and I'm pretty upset today. Eliminate the smoke screen and just be honest. You should deal with feelings immediately and not suppress them.

Support Groups: Support groups are greatly needed for the staff. It is an opportunity for the staff to become more educated by exchanging tips. It is also a good opportunity to discuss topics of concern. For example, a staff member expressed feelings of helplessness for when they can not deal with the residents adequately. One suggestion made was to incorporate the family's plan of treatment with their own. Alzheimer's residents will not get better. This is something the staff had difficulty dealing with. The best thing that can be done is to comfort and support the resident and try to give them the best quality life they are capable of today.

1st Problem: The resident has difficulty verbally communicating with you.

2nd Problem: The resident has difficulty understanding, or processing, what you are saying to them.
say to them.

The resident may be able to read but not understand what they read.
[Example of resident seeing sign "Wet Floor" so resident 'wets on the floor']

They can't understand concepts. It is hard for them to process words into concepts.
-They can't remember names
-They make up their own vocabulary.

[Staff example: "Are you ready to eat?" "No I'm not ready to eat!" But when you feed them they eat.

Mary

Sometimes you get fooled by the resident. When you listen to what they are saying the you realize it doesn't make any sense. Someone just walking by would hear a language structure and not realize it was not making sense. The resident can cover well for their deficiency in

language. Example: To resident "Where do you live?" Resident "Don't you know where I live?"

-Later they can say yes and no only, yet they don't know the difference.
-Eventually, they don't communicate at all, they just have utterances and cries, no verbal communication
-In the terminal stage they are very mute and non-responsive.
-We need to help these people to communicate in some way and to give them better skills.
****

(2nd problem discussed) To get resident to understand (or process) what you are saying to them.
-You may interpret their not understanding as in appropriate behavior, or stubborness or being uncooperative.
-They probably just don't understand what you're saying--they're not processing it.
-Or they understand the first part of your statement but when you reach the second part of your statement they've forgotten the first part.

Nelly

This is a good time t communicate verbally with the resident. [Volunteer acts like an agitated person, as Nelly tries to calm her verbally. Then she puts an arm around the resident's shoulder and calms her down]

Different types of touch. Touch that is very calming or touch touch that communicates frustration. Disease attacks the verbal concepts.

Try and make the resident comfortable. Verbally communicate your understanding. We do not know how much they can comprehend. Guess how they are dealing with certain situations. [Example: "Does it make you uncomfortable taking a bath."]

Try and use words that you know your resident uses and understands.

Talk to them on an adult level. They are not children. When you are talking look for signs of withdrawal. Are they restless and frowning, if so try coming back at another time.

Allow them time to communicate their ideas. Encourage them to communicate. Listening carefully to what they have to say even if it does not make sense. Respect them for an idea. To them it means something.

Pick up on their non-verbal communication. Make sure you are correctly interpreting what they're trying to say.

Keep promises to the resident. It helps gain their respect.

They seem to respond to the we better than,"I want you to do this"

Try and transits what has worked with the resident to the next shift. This helps minimize confusion.

By going through activities step by step you are communicating therapeutically to with the resident. These are simply communications of daily living.

Quality life for a demented resident is being able to be comfortable.

There is no magical situation when dealing with the resident. The best thing to do is try and help improve their daily living. Laugh with the resident not at them. This is okay may even help the resident feel better about themselves. Reflect back tell them what they just did was funny.

Communication Skills

Attending: Totally, cognitively, physically, and emotionally positioning yourself that you are going attend to someone at that communication level. Totally concentrating and not being distracted. Attending to the resident with everything you have. My heart, my head, my soul, my brain, my skills are all involved in providing for them.

Listening:

Empathy: Sympathy is a type of judgement because you don't appreciate what they have in their life. [Example: I know it's very hard for you to give up your home and everything you have]

Respect: Don't assume you know what to call the resident.

Accepting: Really don't know what's going on with the resident unless you know where they are coming from. The things that the family went through when they arrived. What were they like. What they went through between the time they were diagnosed and when they came to the nursing home. What kind of value system are they coming from. Where they are at emotionally. What type of occupation did they have.

Sometimes we equate value with what a person can do. We value the mind. We are human beings we all have the same value. Even though you may disagree but still accept them.

Assertive vs. Aggressive: Okay to be assertive but not aggressive. Should be able to transmit your needs without being aggressive. With demented residents you need to be careful that your assertiveness is not interpreted as aggressiveness. If you come on to them in a authoritarian way it does not work. A lot of the demented residents seem to be stuck. Short term memory goes first-long term memory goes last. [Example: they can remember the price of nails 20 years ago]. They can go back to their childhood and remember every explicit details.

Reminiscene-repeat themselves. Their stories validate their present. They need to tell you I'm okay now because I have accomplished these things. They remember what happened in the past better than they remember what's happened right now. All elderly people reminiscence. Studies indicate their concept of themselves is from being able to reminiscence. When you get old you don't switch personalities-you keep who you were but it is emphasized.

How to respond to resident who act like babies. How far should we go with reality orientation? Deal with it in terms of daily living. You can tell them things several times over and they still will not comprehend. Arguing with them is not affective. Ask them what they are trying to say [Example; "Are you lonely? "Do you wish someone was here to comfort you?"] Arguing and correctly them only frustrates them because they can not correct these skills.

Straight Talk: Take words at face value.

Basic communication skills which will help us grow and make your job much easy.

Communication Problems:

-Not understanding directive
-Reducing resident/staff hostility
-Staff takes communication for granted
-Repetition with from the resident

Staff members need a support group. Need a vent where you can share experiences with one another. Meeting with some other who have some common problems.

Hallucination are a part of communication problems. If resident is so upset because they see things crawling on the wall-then it is time to prescribe a drug.

How to you communicate calmness? Nothing you can do if fear are a result of chemical inbalance. Hallucination occur at the second stage of the disease.

There are three stage in Alzheimer

1st stage: Is very subtle-usually just shades of things. We don't know what goes on until a problem occurs such as they don't pay their bills. (2-4 years)

2nd stage: They have difficulty with such things as walking and speech. (4-6 years)

3rd Stage: Terminal stage. (1 year)The average length of the disease is 8-10 years.

The earlier disease attacks the shorter period the disease is. When the disease starts at an later age it lasts longer. The immune system is similar to that of cancer.

Don't confuse Alzheimer's with Dementia. Alzheimer's is just a part of the pie of Dementia. Alzheimer's is irreversible.

Problem Solving: Dealing with feelings of helplessness. One solution is to use supportive type of things. Change your goals because they will not be getting better. Goal-give them the best quality life they are capable of today. Need support group to help deal with feelings of helplessness. Also, support groups educate you-exchange of information. You should feel good about yourself. Get tips from family.

Tend to ignore sexual expression by resident. How do we feel about elderly and their sexuality? The fact that you are comfortable with your sexuality helps dissolves the situation.

Getting personally involved-caring for the resident emotionally an physically.

Must not have conditional caring when dealing with the resident-should have unconditional caring. Don't make resident think you care if they perform for you. [Example: you eat and I'll be proud].

COMMUNICATION EXERCISE

THIS EXERCISE IS DESIGNED TO REFRESH YOUR MEMORY ON THE LAST IN-SERVICE. THIS IS NOT A TEST, BUT A TOOL FOR IMPROVING YOUR CAREGIVING SKILLS. FEEL FREE TO SIT DOWN WITH ONE OR MORE OF YOUR FELLOW STAFF MEMBERS AND WORK ON THIS EXERCISE TOGETHER.

THERE ARE FOUR SECTIONS TO THIS EXERCISE. PLEASE ANSWER THE QUESTIONS AFTER EACH SECTION BEFORE PROCEEDING TO THE NEXT SECTION.

AFTER YOU COMPLETE THE EXERCISE MAKE SURE THE LAST FOUR DIGITS OF YOUR EMPLOYEE NUMBER ARE WRITTEN IN THE SPACE PROVIDED ON THE NEXT PAGE. THEN, TURN THE COMMUNICATION EXERCISE IN AT HELEN PORTER'S OFFICE. AT THIS TIME YOU WILL BE HANDED YOUR NEXT BUTTON. THE CORRECTED EXERCISES WILL BE AVAILABLE TO YOU A FEW DAYS AFTER YOU TURN THEM IN.

THANK YOU.

READ THIS PAGE FIRST

COMPLETE THIS EXERCISE EVEN IF YOU HAVE NOT ATTENDED THE IN-SERVICE

IMPORTANT!!! WRITE THE LAST FOUR DIGITS OF YOUR SOCIAL SECURITY NO. HERE: ____

SECTION ONE

When using communication skills it is important to remember that there is no one procedure that works for all the residents. However, there are some general communication skills which apply when dealing with most residents. But first let's review the disease.

The average length of Alzheimer's disease is 8-10 years, but it can last for as long as twenty years. Do not confuse Alzheimer's disease with Dementia. There are several types of Dementia. Alzheimer's disease is just one type of Dementia. Some types of Dementia are curable but Alzheimer's disease is not curable. It is a terminal disease.

There are three progressive phases that Alzheimer's disease afflicted people go through. The first phase, is called the "forgetfulness phase", can last from two to four years. The signs and symptoms are so subtle that the afflicted person often does not realize them. They can still function in social and employment roles, drive the car to familiar locations, but have difficulty remembering names of familiar places and objects. They may try to conceal their memory problem.

The second phase of Alzheimer's disease is called the "confusional phase". This phase can last many years. The person has a hard time in demanding work or social situations. Their mood and sleep patterns may become very irregular.

The third and final phase of Alzheimer's disease is known as the "terminal phase" or the "dementia phase". This final phase begins when afflicted persons can no longer survive if left on their own. It is in this third stage of Alzheimer's disease that most afflicted people are placed in nursing homes.

PLEASE ANSWER THE FOLLOWING QUESTIONS. The answers to the questions are contained in the paragraphs just above. Remember, there is more than one correct answer to each question. Circle all the correct answers.

1. In the "forgetfulness phase" of Alzheimer's disease, which last two to four years, the afflicted person:

   a) can still function in social roles and employment roles.
   b) could never drive a car.
   c) may try to conceal their memory problem.
   d) can still remember names of familiar places and objects without any difficulty.

2. The second phase of Alzheimer's disease:

   a) is called the "confusional stage".
   b) lasts for six months or less.
   c) affects the mood and sleep patterns of the afflicted person.
   d) makes it difficult for afflicted persons to deal with demanding work or social situations.

SECTION TWO

There are two ways to communicate, verbally (talking) and nonverbally (through touch or "body language").

Touch is important because it communicates concepts, feelings, thoughts, and warmth through the senses. If a staff member is pushing and shoving, instead of being gentle, an Alzheimer's resident can not understand this action because the disease attacks the brain's ability to deal with such concepts (a concept is something that you can not see, like "a good time"...you can have a good time but you can not see a good time).

Understanding means communicating to the resident that you understand him. To help accomplish this, approach the resident from the front, call the resident by the name he prefers to be called, use eye contact as much as possible, get on the resident's level and not above him, and lean forward when speaking to him. Then, when you talk, use a calm manner, and speak slowly and distinctly. Your tone of voice should always be gentle. Use a simply worded statement and repeat it until the resident understands.

Do not ask a question which the resident can answer with a simple yes or no. In later stages of Alzheimer's disease residents may not know what "yes" or "no" mean. So do not take for granted that the

resident remembers things which you consider simple. Break down tasks to one thing at a time.

Attending skills are those that convey warmth and concern to the resident. You should not rush the resident because he can not understand this behavior. An Alzheimer's resident may not remember how to rush. Also, the staff member should be careful that a resident does not get attached to him/her. If that staff member should leave, the resident may stop functioning properly.

PLEASE ANSWER THE FOLLOWING QUESTIONS. The answers to the questions are contained in the paragraph just above. Remember, there is more than one correct answer to each question. Circle all the correct answers.

3. Touch is important because it can communicate ____?____ through the senses:

   a) concepts
   b) feelings
   c) thoughts
   d) warmth

4. A good way to talk to an Alzheimer's resident would be to:

   a) stand behind them and speak in aloud voice.
   b) approach them from the front, look them in the eye, and speak gently.
   c) speak quickly and stay at least an arms length away.
   d) use a calm manner, and speak slowly and distinctly.

5. When asking a resident to do something you should:

   a) break the task down into step-by-step instructions.
   b) give a harsh and direct order so they will hurry up and you can finish all your work on time, like "Don't sit in that chair!"
   c) remember that the Alzheimer's resident may not remember even the simplest functions of everyday life.
   d) phrase a question so that he can answer with a simple yes or or no answer.

SECTION THREE

Empathy is seeing that you can understand and put yourself in the resident's shoes. The staff member should empathize with the resident, but not sympathize with him.

Respect can not exist without the four preceding skills (Touch, Understanding, Attending, Empathy). Respect can be shown in many ways. Call the resident by the name he likes, for example.

Accepting means accepting the resident the way he is. It is helpful to know something about the resident's past. This can help you understand and accept him. Check the resident's medical record for his Social Service Assessment.

PLEASE ANSWER THE FOLLOWING QUESTIONS. The answers to the questions are contained in the paragraphs just above. Remember, there is more than one correct answer to each question. Circle all the correct answers.

6. Empathy:

   a) is the same as sympathy.
   b) means to place yourself in someone else's situation in order to understand them better.
   c) can be transmitted to a resident verbally.
   d) is different from sympathy.

7. To have respect for a resident with Alzheimer's disease you must know how to use which of the following skills?

   a) touch
   b) understanding
   c) attending
   d) empathy

8. To be accepting of an Alzheimer's resident it would be helpful to:

   a) know as little as possible about the resident's past.
   b) know something about the resident's past because it can help you understand them.
   c) check their "Social Service Assessment" to know what sort of things they did in the past.
   d) all of the above.

SECTION FOUR

Self-revealing means being honest with the resident. Tell him how you feel, whether it is good or bad. Do not bring all your problems to work and dump them on the resident. But, you can admit that things are not going well. Just be honest. By sharing of oneself it invites the resident to open up.

Assertiveness versus Aggressiveness: It is okay to be assertive when caregiving, but it is not good to be aggressive. You should be careful that your assertiveness is not seen as aggression by the resident. Alzheimer's residents may not understand aggression.

When you are caring for residents, pick up on their non-verbal communication. Remember that the Alzheimer's resident has difficulty verbally communicating. They also have difficulty understanding, or processing, what you are saying to them. There is no magical situation for dealing with the resident. The best thing to do is to help improve their daily living. Laugh with the resident (not at them), it may help them feel better.

Support Groups can be a great help to staff members. It is an opportunity for the staff to become more educated by exchanging tips on caring for the residents and a chance to share the frustrations of caring for certain residents. This could make your job more pleasant, a little easier, and improve the residents "Quality of Life."

PLEASE ANSWER THE FOLLOWING QUESTION. The answer to the question is contained in the paragraphs just above. Remember, there is more than one correct answer to each question. Circle all the correct answers.

9. A staff support group would:

   a) be a good place to exchange tips on caring for residents.
   b) offer a good opportunity to share some of the frustration of caring for residents with fellow workers.
   c) be the place to complain about anything and everything related to working in a nursing home.
   d) a chance to share ideas on ways to improve resident care and make your job more pleasant.

DID YOU REMEMBER TO INCLUDE THE LAST FOUR DIGITS OF YOUR EMPLOYEE NUMBER?

Estimated time: 90 minutes

Domain:

Objective: At the conclusion of this training, the participant will be able to:

1. Define the following terms and distinguish between them.

   Memory loss
   Speech changes
   Perservation
   Judgment
   Attention span

2. List a minimum of four care procedures to care for the Alzheimer's Disease resident.

3. Discuss the differences in each of the three progressive stages of Alzheimer's Disease.

Evaluation Criteria

Without error complete the Care Strategies exercise.

Learning Resources

Primary

1. Study Guide

2. Dyck, Arthur J. "Ethical Aspects of Care for the dying incompetent," Journal of the American Geriatrics Society, Vol. 32 no. 9, September, 1984, pp. 661-664. (reprint).

3. Kellett, John M. "Education in dementia for the caring professions," Danish Medical Bulletin, Vol. 32 Supp no. 1, February, 1985, pp. 67-71. (reprint).

4. "Senility Reconsidered" JAMA, Vol. 244 no. 3, July 18, 1980, pp. 259-263.

5. Glosser, G., Wexler, D., Balmelli, M. "Physicians 'and Families' Perspectives on the Medical Management of Dementia," Journal of the American Geriatrics Society, Vol. 33 no. 6, June 6, 1985, pp. 383-391.

6. Hall, G., Kirschling, M.V., Todd, S. "Sheltered Freedom-An Alzheimer's Unit in an ICF," Geriatric Nursing, Vol. 7 no. 3, June, 1986, pp. 132-137.

7. Riesberg, B. et al. "Remedial Behavioral Symptomatology in Alzheimer's Disease," Hospital and Community Psychiatry, Vol. 37 no. 12, December, 1986, pp. 1199-1201.

8. Gwyther, Lisa P. "Care for Caregivers," Journal of Gerontological Nursing, Vol. 9 no. 2, February, 1983, pp. 93-95.

9. Gwyther, Lisa P. Care of Alzheimer's Patients: A Memorial for Nursing Home Staff, 1985.

10. Heston and White. Dementia. 1983.

Key Words:

Neurological	Depression
Brain tissue	Vascular disease
Primary Dementia	Autopsy
Secondary dementia	

CARE STRATEGIES

Quality care for a demented patient sometimes begins and ends in the home setting; however, many families choose to institutionalize their demented relative. Some consider home-based care more advantageous than institutionalized care. Family care is generally perceived as being more individualized to meet the special needs of a demented individual. Generally, one feels that families can provide more affection, dignity, compassion, and patience. More direct personalized care for the patient versus that received in an institution is often cited as another advantage. In-home care may range from complex, technological, sophisticated innovations to home-delivery methods. Between these extremes lie: skilled nursing care, physical therapy, speech therapy, personal care, and chore services. In either setting, the definition of quality care becomes difficult. Quality care may encompass a full spectrum of long-term care and a variability of individual needs and preferences.

An adequate program of care in the family may begin with the acquisition of an early diagnosis when abnormal behavior is witnessed. The primary caregiver should periodically assess the dementing person's needs. S/he should determine the degree of the afflicted's memory loss and disorientation, social skills, agitation, and sleep patterns. The family member may also wish to provide protection, safety, social stimulation, and comfort for the patient. When a caregiver feels that s/he has exhausted all skills, s/he may opt for institutionalized care.

Providing a program of institutionalized care to encompass the needs of an Alzheimer's patient can become a complicated process. Complications exist, not because skilled care is needed but, rather that various tasks are time

consuming. An ideal care program should recognize the patient's family as clients and include an assessment of the family's needs and capacities, as well as the patient's. The prospectus should be specific. Furthermore, long-term care should address the physical, functional, mental, and emotional needs of both the infirmed individual and his/her circle of relatives and friends.

A prototype program of care should be more specific than just to encourage independent functioning. During the admissions process, a detailed list should be compiled of what the patient can do alone versus what the patient can perform with assistance. One might also include those tasks which require total assistance. Individual priorities, therefore, should be established. The staff should be encouraged to tolerate any routine or preference solicited by the patient or the family as long as interference does not occur against other's rights.

Managing symptoms, adapting the environment to one's capabilities, rotating or not rotating caregivers, and performing daily routine tasks should be primary objectives of an institution's staff. Proper management focuses upon recognition of intellectual impairment and personality and behavior problems in order to promote optimum functioning and adjusting. It is essential that staff members interpret nonverbal cues to pain, discomfort, urgency, or worry; because, many times Alzheimer's patients cannot articulate their feelings. No drug exists which can miraculously cure Alzheimer's disease. Psychotropics, however, are used and have altering effects on the mind. Psychotropics may ease some of the more distressing concomitants of the disease. These drugs include: tranquilizers--to relieve agitation and violence, or antidepressants to relieve depression. Care should be taken to provide proper dosages and to eliminate abuse.

Staff members are responsible for establishing an environment, conducive to a patient's needs. The environment should be of utmost quality and structure, appealing to a resident's definition of quality--rooms, bathrooms, and common rooms should remain tidy at all times. The outside area should accomodate those patients with ambulatory problems. Exercise equipment is suggested as well as a fenced-in area to avoid wandering from the premises. Overall, the established environment should comply with the realistic, achievable outcome for all individuals seeking long-term care.

Different views have been expressed relative to the necessity to rotate staff members. Some consider constant rotation as a tactic, providing confusion to the afflicted individual. The demented patient may have difficulty remembering many faces. On the other hand, rotation may be advantageous. In this respect, caregivers can avoid physical and mental fatigue. They (the caregivers) are capable of experiencing different cases throughout the process. Either way seems reasonable. The chosen method should be in-sync with the level and abilities of the staff.

Care procedures should be documented on a daily basis as to the time of implementation and as to whom will supervise the various tasks. Activities should be considered with the patient's past and present condition of mind. Staff should maintain consistent routines, utilizing matter factness, repetition, consistence, and good humor. Activities may include playing with small kids, who are not fearful of a demented patient's lack of responsiveness. Routine exercise can be stressed as a means to alleviate tension. Leisure activities are possible as long as they remain simplistic. Other activities such as personal hygiene and grooming should be done on a daily basis and in a caring manner when assistance is needed. The patient should always look presentable. The other appearance will gain appreciation from family members,

visitors, and other residents. Cleanliness also enhances the willingness to demonstrate affection, via touching. One may even consider praising an individual and providing complements to express love and concern.

Many Alzheimer's patients develop bowel and bladder problems--bedwetting and incontinence. A routine should be established, whereupon an individual will be required to use the toilet at established times. Fluid intake, however, should not be reduced; because doing so may promote dehydration.

Other recommended activities include interactions between caregiver and patient. The caregiver should speak in a quiet voice, with undue emphasis. A patient should never be scolded for mistakes. Patients probably will not remember if you told them they did something wrong. Adequate communication must always exist with the Alzheimer's patient. Furthermore, when talking to a family member, the positive should be accentuated--i.e. don't say s/he cannot dress him/himself; instead say the patient is doing fine--s/he can feed him/herself. This positive reinforcement enables both the patient and family to feel comfortable and relieved. The following do's and don'ts have been suggested in the literature for staff members to enable the provision of exemplary care to a demented individual:

DO'S

--Keep everything simple as possible.

--Expect the Alzheimer's patient to ask repetitive questions.

--Give the patient simple tasks to perform.

--Provide a period of respite.

--Show affection towards the patient (hugs, touching, patting, etc...)

--Reassure and praise the patient, indicating trust.

--Maintain a proper diet for the patient.

--Convey a feeling of security, via soothing words.

--Give instruction one step at a time.

--Ignore things which annoy.

--Remain calm and pleasant.

--Get ample rest.

--Provide recognizable pictures--these pictures can be the stimulus for conversation.

DON'Ts

--Expect accurate answers to questions.

--Get irritated when patients ask questions, repeatedly.

--Give instruction and expect perfect implementation.

--Give a patient too much responsibility.

--Expect to be able to identify all words, names, and faces.

--Take a patient's behavior, personally.

--Argue with the patient.

--Try to provide solo care.

--Give a patient a choice--choosing can become confusing.

--Get upset.

Consistent staffing is important to implement any care program. All staff must be trained to work with demented residents. The above do's and don'ts will be implemented to a higher degree if staff members are well informed to the needs of their patients. This list encourages social interaction. It provides adequate and appropriate staff to encourage autonomy. Furthermore, implementing these ideas will create a personalized environment and privacy for each patient.

Staff should involve the family in the total care plan. Relatives should feel comfortable visiting, making suggestions, and even grooming their relative with the staff's consent. An active family, in most instances, will feel content that everything possible was done to prolong their relative's life and ease the period in which death was imminent. The actual outcome represents changes over time indicating the actual measurement of quality care.

IMPORTANT!!! WRITE THE LAST FOUR DIGITS

OF YOUR SOCIAL SECURITY NUMBER HERE:_____

CARE STRATEGIES

THERE MAY BE MORE THAN ONE CORRECT ANSWER. CHECK ALL THE CORRECT ANSWERS.

1) When a resident has lost the ability to use the muscles of the tongue, she/he

   a) will grow weaker from less food intake.
   b) can not chew TOPPS bubble gum.
   c) may be encouraged to eat a colorful plate.
   d) should avoid foods that may choke her/him.

2) Cognitive loss is the inability to do things for herself/himself. As a caregiver I can

   a) let her/him talk about old times past.
   b) put pictures of things she/he uses around the room.
   c) do everything for him/her.
   d) get angry because the resident won't try to do things.

3) When a resident has lost the knowledge of how to do things for herself/himself, as a caregiver I can

   a) use reality orientation on her/him.
   b) ask the family to bring pictures from home.
   c) keep familiar object in the same place (eyeglasses, watch, clocks, calendars, etc.)
   d) assist with dressing and selecting clothing.

4) Incontinence is the loss of control of bowel and bladder functions. As a caregiver I can assist the resident by

   a) using incontinent pads, diapers, chucks, etc.
   b) putting the resident on a two hour schedule.
   c) making a record of her/his patterns of elimination.
   d) showing my disappointment when the resident has an accident.

5) When a resident suffers from impaired communication, I should

   a) point, touch or hand resident objects.
   b) use short words and simple sentences when they don't understand.
   c) repeat the same sentence with the same words.
   d) not let my body actions or facial expressions interfere with communication.

6) The resident who becomes malnourished or dehydrated may

a) have difficulty swallowing.
b) not be able to use a knife or fork.
c) develop abnormal eating habits.
d) want the family to feed her/him.

7) List three (3) things you can do to help the resident who could be injured because of impaired physical mobility.

a) _____

_____

b) _____

_____

c) _____

_____

8) Here are some nursing interventions I can use in caring for the resident who does not communicate very well. List three (3):

a) _____

_____

b) _____

_____

c) _____

_____

LAST FOUR DIGITS OF SOCIAL SECURITY NUMBER ON FRONT?

CARE STRATEGIES

NURSING DIAGNOSIS

Potential for injury because of impaired physical mobility.

Symptoms: becoming lost; wandering behavior; restlessness at night; constant or agitated pacing; changes in gait; stance is wide based and steps are slow and shuffling; posture is stiff and stooped; balance and steadiness interfere with self care.

NURSING INTERVENTIONS

--Help with walking. Take on frequent walks
--Remove clutter
--Keep occupied and active during the day
--Lower light intensity with shades
--Direct attention. Keep occupied at a task
--Sit resident and elevate her/his feet

NURSING DIAGNOSIS

Changes in patterns of elimination. This is caused by sensory motor impairment and decreased mobility.

Symptoms: decreased ability to hold large amounts of urine; unable to locate bathroom; eliminates (defecates) in inappropriate places.

NURSING INTERVENTIONS

--Identify (record) patterns of eliminations
--Offer bedpan or take to bathroom every two hours
--Use adult incontinent pads, diapers, chucks etc.
--Provide easy access to toilet
--Provide condom catheter for men and correct collecting bag
--Keep indwelling foley at minimum
--Provide perineal care
--Restrict fluids at night

NURSING DIAGNOSIS

Impaired communication. Usually caused by gradual loss of cortical areas of the brain which control memory, language and motor functions controlling speech patterns.

Symptoms: Resident shows strong nonlistening behaviors; may use verbal abuse with family or caregiver; in severe cases, all verbal abilities are lost and speaks by grunting.

NURSING INTERVENTIONS

--Approach resident unhurriedly, slowly
--Use slow clear and distinct speech,and wait for patient to respond
--Reassure verbally and by touch
--Ask one simple question at a time. If repeated, ask it exactly the same way
--Maintain calm body language. Do not appear impatient or annoyed
--Use signals other than words. Point, touch, or hand resident objects
--Use short words and short simple sentences
--Lower pitch (or tone) of voice. Do not speak loudly
--Ask resident to do one task at a time
--Carefully assess the resident's body language to determine pain or discomfort when resident is no longer able to talk or verbalize

NURSING DIAGNOSIS

Difficulty in swallowing. Chance of malnutrition or dehydration.

Symptoms are: loss of table manners; loss of ability to use knife and fork; doesn't eat or develops abnormal eating habits. Caused by loss of ability to use the muscles of the tongue.

NURSING INTERVENTIONS

--Eat at same place and same time for each meal
--Remove unnecessary eating tools
--Use plastic dishes and tools
--Prepare foods that are easy to hold and pick up
--Avoid foods that may choke the resident
--Grant special requests for certain items of food
--Cut food into bite-size pieces

NURSING DIAGNOSIS

Cognitive and Perceptual Impairment.

Cognitive is a fancy word we give for our ability to do things for ourselves. Cognitive 'loss' means the loss of knowledge on how to do things we used to always do before. If left on their own, persons with cognitive loss would have difficulty functioning and doing things we do without thinking, like dressing ourselves, activities of daily living, etc.

Symptoms: Inability to recognize self, spouse or family members or other familiar faces; remembers past events; may hallucinate.

NURSING INTERVENTIONS

--Ask family to bring pictures from home
--Do not force the resident to do anything
--Label items with pictures. Ex. place picture of toilet on bathroom door
--Orient to person, place or time
--Allow resident to talk to own reflection in mirror
--Place clocks and calendars in view
--Avoid reality orientation
--Reminiscence with the resident because he retains some knowledge of past events
--Because he remembers the past better he tries to validate the present time by talking of the past
--Assist with clothing choice and/or dressing. Use clothes that can be put on and taken off easily

INSTRUCTOR'S GUIDE FOR FAMILY BURDEN EXERCISE

ESTIMATED WORK TIME: 90 minutes

DOMAIN: Family acceptance and coping with a senile demented relative

OBJECTIVES:

1. The participants will be able to define and distinguish between the following terms:

Denial	Dementia of Alzheimer's Type
Anger	Grief
Guilt	Role change
Depression	

2. List six affective emotions the family experiences.

EVALUTAION CRITERIA:

Without error complete the questions in the Family Burden Exercise.

LEARNING RESOURCES:

Primary

1. Study guide
2. Mace, Nancy L., and Rabins, Peter V. The 36 Hour Day (John Hopkins University Press Baltimore).
3. Gwyther, Lisa P. Care of Alzheimer's Patients: A Manual for Nursing Home Staff (American Healthcare Association, Washington D.C.).
4. Rabins, Mace and Lucas "The Impact of Dementia on the Family," JAMA. July 16, p.3 (reprint).
5. Gwyther and Blazer. "Family Therapy and the Dementia Patient," American Family Practice. Vol. 29 no. 5, May, 1984, pp. 149-156. (reprint).
6. Kohan, Kemp, Staples and Brummel-Smith. "Decreasing the Burden in Families Caring for a Relative with a Dementing Illness," Journal of American Geriatric Society. Vol. 33 (10), Oct, 1985, pp. 664-670.
7. Mace. "Families: The Other Side of Alzheimer's," Provider. Vol. 12 no. 5, May, 1986, pp. 22-25. (reprint).
8. Luke. "Alzheimer's Disease-Family Support," Psychiatric Nursing. Vol. 24 no. 3, July/August/September, 1983, pp. 8-11. (reprint).
9. Hayter. "Helping Families of Patients with Alzheimer's Disease," Journal of Gerontological Nursing. Vol. 8 no. 2, February, 1982, pp. 81-86. (reprint).
10. Video Tape. "The Caregivers Dilemma: Detecting Treatable Medical Problems in the Alzheimer's Patient" Kenneth Brummel-Smith, M.D., Distributed by the Office of Media Services, University of Southern California, School of Medicine.

THE FAMILY'S BURDEN
STUDY GUIDE

NURSING DIAGNOSIS

The family begins to notice some loss of memory, and that the relative doesn't remember familiar persons, objects or places; behavior may be unpredictable.

Symptoms: recent memory fails; one can no longer remember where they live or how to get there; familiar people are strange; time is not important; has outburst of anger, or crying; family is embarrassed over inappropriate behavior; forgets how to do routine things; appears restless.

Family members: becomes tired of repeating themselves with long explanations to resident's questions; are embarrassed by resident's behavior in public and among friend; fear criticism from others; attempt to treat the relative as "adult" as they used to know him/her.

NURSING INTERVENTIONS

--Caregiver must treat the resident gently and deal with her own frustration and sadness by talking to a friend.
--Encourage the family caregiver to look for and enjoy small things the resident can do alone.
--Be patient and understanding with the family.
--Show interest and concern with eye contact and a meaningful touch by holding their hand in both your hands.
--Let the resident do all that he/she is able to do alone.

Understanding the Family Burden

Alzheimer's is a progressive neurological disorder. Symptoms include: memory loss, judgmental changes, and personality and behavioral modifications. It's irreversible and presently no known cure or treatment exist. Over two million Americans suffer from Alzheimer's. In the early stages of the disease, the patient becomes forgetful. Perhaps, one has particular trouble remembering current events. One might also lose things, forget how to perform routine tasks, and have difficulty remembering names--even those of close friends. As the disease progresses, memory loss increases. Irritability, confusion and restlessness may also occur. The patient's ability to reason and function continues to decline. In the most severe cases, patients are unable to care for themselves. They remain at home until very late in their illness. Caring for a patient with Alzheimer's disease can be stressful.

The stress encountered within the families of these patients and the experienced burdens are of significant interest. Within an institutional setting, this dementing illness sometimes progress unknowingly. The individual's family, however, is usually more cognizant of behavioral changes and memory deficits. Families of Alzheimer's patients experience many burdens.

The family's first burden is to determine the essence of one's behavioral change--some hypothesize neoplasms (tumors); others, strokes. They recognize abnormalities and the need for a medical assessment. Relatives also do not wish to consider spontaneity--i.e., it was not as if a patient were not feeling well and all of a sudden fainted or fell to the floor, being unable to return to an erect position. The process of the disease is very subtle.

Finding a physician who is able to provide a proper diagnosis is a very difficult task. One wishes to obtain a physician who will evaluate the situation and provide comfort and direction to the family. Usually, families provide a medical history prior to the physical examination. Some physicians, unfamiliar with the clinical presentation of Alzheimer's, may attribute the clinical observations to old age and a subsequent memory loss. The advise given is to not worry, go home and provide care, and everything will be okay. Some physicians may say well, they are really getting old, and inquire if one is willing to provide care. The physician may then suggest to find a nursing home for the patient. These responses are quite common.

Physicians are becoming more knowledgeable about this disease. Five years, ago, many medical professionals were unfamiliar with Alzheimer's--many would respond--what are your talking about?--These are senile people-they are old-this is normal. It is just amazing that many take it for granted that physicians may know all the stages of Alzheimer's, the treatment of the disorder, and the help of the

staff--either nursing or other health care staff-needs from the physician in terms of direction. With the above responses a lot of families feel relieved, go home, and do not worry excessively. But, when nothing improves, they become frustrated and begin physician shopping. The problem, however, is not resolved and the frustration increases with increased medical expenses.

Obtaining a reasonable diagnosis really depends on the family's sophistication. An assessment depends of the patient's symptoms--the more severe they are, the more an inquisitive family will demand explanations, relative to the observed abnormalities. The physician will normally respond--how long have the symptoms persisted? Furthermore, a trained professional will ask about financial resources and one's willingness to participate in available diagnostic workups.

The degree of cooperation among family members may vary. Sibling number one may think it is a good idea to take the relative to another city for assessment. Another sibling may think well, this is our family physician--we have been seeing him/her for years. Why change now? So there are conflicts as to what family members should do and what to do in those initial stages. This sets the tone for what families will experience throughout the process of the disease. The family in this stage already disagrees in terms of what they are going to do next. These discrepancies may affect later interactions as the disease progresses.

Defining "patient" is a difficult process. Patient now describes the family. The patient is not the victim of Alzheimer's disease. The term, patient, encompasses the entire family and the primary caregiver. In a clinical setting, patient references and individuals who have a diagnosis and a chart. The term must be extended! Conceptually, one has to consider the family that may not have a relative in a nursing home, hospital, outpatient facility, or in a daycare situation. The family is really the patient for whom a plan of care and treatment should be developed. As this inservice is developed today and advances made, the extension of familial involvement may become better focused.

Should a patient be informed of an Alzheimer's diagnosis? Consider the following scenario: memory losses, ill feelings, forgotten residencies--should we tell the patient? Is this an ethical/controversial issue? Some responses have been:

(1) I don't think so. I think if you tell them, they wouldn't remember anyway.

(2) I think they know something is wrong.

Both family as the patient and inflicted individual know something is not right. Some convalesced residents who are in neither the last stage nor late middle stages of the disease are institutionalized because of family situations. They know that they are forgetting, but they are not able to provide any logical explanation. Explanations are needed when these events surface.

The philosophy is to tell the patients that they have a neurological disease. The tendency is not to call it Alzheimer's because no one is sure that it is Alzheimer's until the time of the autopsy. Again, the etiology remains unknown. Help in adjusting, however, is provided as the disease progresses. Some accept the diagnosis; others, deny it. Perhaps, one may establish that denial is a function of actual memory loss.

In the early stages, excessive denial occurs within the victim. Also, they have the capability of covering up their memory loss in an amazing way. They can fool health care people--they can fool their doctors--and of course, they can fool their friends and relatives. Rarely, do they fool the primary caregiver--the one that lives with them day in and day out. But, they can fool their doctor! Visits are short--the doctor is busy. Improper diagnoses are often made because of vague responses. The patient, however, is to be commended for attempting answers--one may with to attribute this responsiveness to past social contacts.

Concurrently, the family also denies the diagnosis. Two levels of denial exist. The first is an intellectual denial, encompassing a family member restating the doctor's diagnosis of Alzheimer's; but, adding a probability clause of decreased severity of the illness and hope for recovery. Secondly, emotional denial involves one accepting the informity as okay. The latter group has not truly assessed their feelings nor the problems which may exist in the future. Unlike the intellectual deniers, the emotional deniers received brochures and verbal information, detailing the disease and its progress. The emotional deniers continue to discard the emotional aspects this disease could present, relative to preparation and understanding. Some families deny both-they become angry with the doctor and the underlined diagnosis and proceed to find another medical provider--this may encompass emotional denial.

How does one confront these denial patterns? One of the most important things is that the relationship with the family remains open. We cannot confront the family and say, you are denying what we are telling you--we do not think you are facing reality--we want you to realize that this diagnosis is accurate. These statements provide additional defenses--an individual is proned to reject all advise. Instead, we should say--maybe at this time it is hard for you to accept what we are telling you, but we need to see you again.--It is important that we continue talking about this.--If you are not ready next week, call us and we will be here to discuss any further changes. Families will generally return, because symptoms will increase and they will be at a probable loss if they did not return. The victim is sometimes taken to another doctor, continuing the process of "doctor shopping" rather than accepting the presented facts. The key is to be flexible--understanding the status of the family and the ongoing conflicts in their lives.

After accepting dementia, and if Alzheimer's is in progress, a second familial burden ensures. A tremendous amount of anger and

resentment persists. The responses are natural and are directed to the victim. The primary caregiver is usually trapped in a very long term care giving relationship. Past responses have been: I have to quit my job--I may need to stay home--I will lose my social life--my routine is totally changed. The patient becomes irritable, aggressive, abusive, resentful and angry at that stage. Consequently, the family becomes helpless and hopeless.

Anger is also expressed between family members, because the emotional reaction of the family is to deny the disease's severity. When siblings visit, the informed generally suppresses the nature of the illness. Usually, the demented family member is capable of conducting an intelligent conversation. The exchange may be: "How are your kids?" Well, anyone can ask this; but, the inquirer cannot remember the names of the kids. Furthermore he/she does not remember what school the children attend or if and when the children are even seen. The responses and questions are general; after which, the sibling may say to the primary caregiver--what are you talking about?--He/she just conversed--he/she is eating well--he/she looks well--I don't know what you are talking about. So, anger and resentment are prevalent among siblings.

Choosing the primary caregiver is also problematic. The primary caregiver is usually the oldest daughter or the youngest daughter or the one that has not been married. So the attendant resents the family dynamics through which he/she was subtly chosen. Actually, one is chosen before the disease's onset. Caregivers resent that position--they may not be able to do anything about it. They may be rather angry, but avoid expressing that resentment towards other family members. To help the cope with anger, other family members and the medical team should accept their feelings, acknowledge their resentment, and provide sympathy. Education is important! Subsequently, the caregiver should strive to maintain a direct focus--he/she should not personalize what the ill person says or does not say, realizing that the diseased state may provoke unintentional statements.

Guild is a common emotional reaction of the family. Families lose their patience. Then, they feel guilty for losing their patience--for yelling back--for raising their voices or saying I'm so tired of you and what you are doing. They feel guilty for saying--I don't want this responsibility. They blame themselves for the deterioration of the victim. Then they say, maybe I'm not doing things right--maybe, I didn't take him/her to the right physician--maybe, I'm not feeding him/her right. These feelings are normal.

Grief is another familial response during the early stages of the disease. Alzheimer's may persist for a fifteen year period, during which the dementing process continues. Grief continues over the period of the disease. Grief pertains to the loss of the relationship--the things once talked about--the things shared together during vacation--jokes--little things that are only exchanged between couples (mother/daughter; father/son; husband/wife; etc...). They grieve the loss of that unique relationship. They also grieve the

loss of social relationship--they cannot entertain their friends as they did in the past. The grief process, however, may occur for different families at different times, depending on the quality of the relationship (caregiver/patient), the age of the patient, and one's ethical and moral conviction. For most families, grief occurs later on in the disease when communication is totally mute--the victim cannot respond to conversation.

The subsequent loss and grief, resulting from institutionalization is sometimes a proponent of death; but, not comparable to the instantaneous death of a loved one in a family from a heart attack or cancer. Grief has already occurred with family members of Alzheimer's patients-maybe, three or four years before. The grieving process is slow. During the period of the wake or the burial, most family members have abandoned their grief. They don't need the support given to individuals who lose a loved one or friend to a sudden death. They have more or less anticipated the infirmed's death for a long time. The actual death represents relief for many families --relief that the suffering is gone--especially, if they have experienced an extended period during which that person was emotionally and psychologically dead. The infected patient is confined to the bed--totally mute and unable to communicate at any level. Some families, however, grieve the most when they decide that they do not want any intervention--tube feeding, antibiotics, and resuscitative measures are eliminated--instead, merely allowing the patient to expire in a natural non-interventive manner. Denying medical intervention is not the most common procedure; but, in most (if not all) cases, the element of grief settles in, regardless of the extenuating circumstances.

Several studies have been compiled, examining the behavioral reaction of the caregiver. One study identified fifty-five family members of patients with dementia. Sixteen Alzheimer's cases were diagnosed in the families of these fifty-five subjects. These diagnoses are only probable. Statistics showed that approximately 87 percent of the family members suffered from chronic fatigue, anger and depression. Fifty-eight suffered from loss of friends and hobbies. Other reflections of that survey were: (1) 31 percent were concerned that the caregiver would become ill; (2) 29 percent assumed responsibility for the person with Alzheimer's disease; and (3) 25 percent experienced guilt complexes. The study demonstrated that the caregiver experiences severe and chronic levels of stress, burnout, exhaustion, and the propensity to develop ulcers. The usage of prescribed drugs and alcohol in excessive amounts has been demonstrated also. Prescribed drugs are dispensed for sleep and motility. Alcohol abuse is attributed to one's inability to cope. Most of these characteristics are seen among family members.

Isolation is a common element for the caregiver--especially, the spouse of the victim, because siblings usually have their own family and their own friends; whereas, a spouse, especially in the older years, is almost a loner. The care is so demanding, eliminating even a simple telephone call to a friend. Social activities are not advocated--one appears totally trapped--totally isolated. Caregivers

also isolate themselves by choice, because they are embarrassed by the patient's behavior in public, which may encompass oddity and awkwardness--usually, a caregiver does not wish to be uncomfortable in those situations.

Respite is a possible cure for isolation. This may be accomplished by bringing family members in to care for the patient while the primary caregiver takes two to three hours a week to shop and/or visit friends. The correlation between isolation and burnout is great. They are able to use that respite in any manner. These short breaks from monotony enable to the caring process to extend for a longer period; also, institutionalization is postponed as much as possible.

The loss of identity is a frightening ordeal for the caregiver (as spouse). The spouse becomes isolated and surrounded by the memories which once existed in the relationship. The constant interaction with someone who is expressing bizarre behavior with a paranoia and delusions substantiate this loss. One loses contact with reality. The phenomenon becomes frightening and one wonders if he/she is dealing with two sick people? Beyond the Alzheimer's patient, the caregiver may experience stress and emotional problems. The caregiver may also question his/her identity and the subsequent ability to perform tasks. If this happens, other family members and the medical staff (if solicited) must now involve themselves with someone on the brink of dysfunctionalism. This becomes a burden on society, the family, and on the social agency because the need to interpret reality. Perhaps, the only way to confront the existing problems is to remove the caregiver from that situation and force him/her into a situation where they are going to interact with adults, who have interests, hobbies--a social life--becoming active--and, proclaiming that my world is not only with my wife/husband who is far removed from reality.

Another burden families suffer--especially husbands and wives--is the inability to express and interchange emotional and social responses. They are not able to demonstrate affection as in times past. They cannot perform sexually. These handicaps increase spousal isolation, while lowering one's perception of oneself. These lack of interactions can become symptoms of depression. They become isolated from any affection because the victim is not able to show any appreciation--any thank you--nor, any emotional response to the caregiver.

Another burden of the family is the role changes. Families need to make many changes. One change involves traditional roles--if the wife has to assume the responsibilities of banking, mowing the lawn, and taking care of business affairs or, if the husband has to cook, clean, do the laundry, and dress and undress the wife. This is a very difficult process--the two are changing roles--especially for the present older generation, because they are coming from a generation where roles are stereotyped--men don't do this;women don't do that. The adjustment can be difficult. For many, this is the time when one

adheres to institutionalization--especially the male, when he is unable to perform the role that his wife used to undertake.

The concept that the child becomes the parent of the Alzheimer's parent is not really accurate. We must never assume the role of our parents, regardless of how old we are or how old they may be. An interesting note is that of a sixty year old lady who states that she cannot do anything without her eighty-two year old mother. These roles never change, but the tasks change--we undertake an additional task as middle aged children--to take care of our parents that may have Alzheimer's disease. This, in itself, constitutes a burden.

We need to differentiate between role changes and tasks which parents and children encounter. Emotionally, many children are relieved to know that they do not have to make this distinction. Myths propose that your parents become like children and you have to take care of them all the time, but emotionally that is traumatic. Regardless of the circumstances, the roles traditionally performed by parents and children should be maintained.

In the disease's early stages, the Alzheimer's patient adjusts to the existing changes. They are aware of their changes and the necessity to give up little things. They usually, however, don't relinquish these duties easily. For example, not being able to drive the car, balance the check book, nor pay the bills provide a motif of depression--because of their semi-awareness of their function-it is not what it used to be. Later on, they are really less stressed and depression decreases. A blank look is seen. But, then as the caregiver changes, the victim changes--then, the whole family changes. The whole dynamics of the family changes. This is when an assessment of the family is important because one has to examine the capability of coping skills needed to handle the situation or whether referrals should be made to an agency, a counselor, or the mental health center. Family members experience headaches and hypertension. Counseling, therefore, is needed to help individuals cope and assist the reestablishment of the harmony that once occurred within the family. Past relations tend to dictate how individuals respond to a relative with a dementing illness. If the relationship were one of harmony, adjustment, feelings, and caring, the odds are that the children are much more accepting of the parent's behavior. If, however, parents/children were in conflict, then guilt, anger, and resentment are superimposed, creating turmoil in the family dynamics.

The above discourse has examined the patient in the family before placement in a convalescence home. Now, we need to examine when the family considers institutionalization. Again, I would encourage you to conceptually think about the family as being the resident--being the group of people with whom major interactions will occur.

The primary caregiver feels strongly that he/she is abandoning the victim. They have not been able to handle the situation. Grief and sadness are prominent emotions during this stage. The reaction of this can be two-fold. One is that to compensate for that guild, the caregiver starts visiting every morning of every day. He/she is there

to feed the patient. He/she is there all the time. Or, one may not visit at all and weeks and months pass and the caregiver is never seen. The ones who really accept their inability to physically continue the care are those who feel that their parents lived their lives and did well--they feel that they are in control and that their own family is important, having made that decision, consciously with preparation--this group probably represents a pretty good family to deal with. Conflicting feelings are avoided. They will visit normally. They will call the institution and chat about the loved one. They are pretty well adjusted people because through they years they have accepted life situations and disease. The relationship has been great.

One the other hand, caregivers who were in conflict exhibit turmoil as they come into the nursing home. They start resenting the staff in the nursing home because the staff is able to do what they have not been able to do. The nursing home staff becomes the target of anger and resentment. Again, as I mentioned earlier that the time of placement is the time of a physical and emotional death. For some, they feel nothing more can be done nor said. The family's emotions should always be understood and accepted. The medical staff, however, should not personalize when they are experiencing--it is really their own feelings--they had to make that decision--the institution's staff becomes the subsequent target of these emotions.

Institutions should be aware of those who visit all the time. Counseling should be referred for these individuals. A constant visitor usually neglects him (her) self--he/she is not eating nor sleeping well--he/she is just too tired to be sitting next to the resident making sure that the institution is properly treating the patient. Excessive visitation is a response to guilt. The institution should be cognizant of the caregiver's needs and should comfort these individuals by reiterating that they provided a great job for their loved one;furthermore, these individuals should be assured that their loved ones will receive the institution's utmost care and attention.

Some families feel terrible because improvement is sometimes evidenced after the placement. Apparent improvement may be attributed to structure, reliability, and routine. Families may be confused at first, but they learn the routine and the plateau gets longer and longer in terms of their behavior. The family sees their relative rather comfortable--they may say, well what happened? What are you doing that I didn't do? The staff member has to reassure them and tell them that the apparent progress has to do with the structure and that the resident becomes acquainted with a routine. Family members are then concerned about other illnesses--they insist that the provider tell them if the patient has a cold or another infection. The general response should be one which ascertains that the institution is providing exceptional care and that if anything occurs, the institution would inform them.

Detecting other illnesses in an Alzheimer's patient can be difficult. An exception tape, "How Do You Detect Other Illnesses in

Patients With Alzheimer's Disease" is recommended. The patient cannot articulate his/her symptoms--they cannot tell you it hurts here or there. They may not tell you they have had urine blockage or blood in the stool. So, how do you detect that? The suggested tape should provide insight. Another common tendency of an Alzheimer's patient is to complain about headaches. This cannot be explained. It is also difficult to explain why patients touch their heads all the time. It has been reported that patients are trying to disclose something about their heads. Now, is that a headache? Is that something they feel is going on? Is it because we associate memory with the brain?--And, they are pointing to their brain. These are areas not currently understood. But, one must always be aware of the propensity for other illnesses and strive to maintain a comfortable atmosphere for the patient.

Families sometimes feel secure that the relative is in a healthcare facility. An orientation to these facilities should be provided during the family's initial visit, during which information is provided and questions and additional visits encouraged. Families leave, knowing that the institution is now capable of providing proper treatment in existing emergencies. One common and frightening emergency is choking. Choking is common in the latter portion of the second stage and in the early stages of the third. Many families become paranoid when this occurs. Therefore, knowing that trained professionals can better confront these problems provided relief and comfort.

It is helpful to develop a newsletter that is sent to families of nursing home residents. Families should be informed of the schedule and activities of the institution. This information should be provided on a weekly basis. This system of communication enables families to directly interact with their relatives and institution's staff.

Guidelines should be established. The family members should be provided with the institution's telephone number and should be encouraged to utilize telephone communication with the proper staff member. Visiting hours are important and should be provided for family members. In this regard, families can feel welcomed, without guessing appropriate visiting hours. Some families feel that this is a way to hide something from them. This is why they want to come at their own free will--to check on the staff member or the institution. The staff needs to help them resolve that paranoia.

"Admissions" should be considered a process and not a specific time of entrance to the facilities. The process starts when families make the initial phone call and say I am interested.--Do you have any beds? What are your procedures? May I see your facilities?--The process of admission starts here and it continues for a month or two after that person enters, because they are still going through that process of accepting the placement, both psychologically and emotionally. Families may have placed the victim physically; but, they have not placed them emotionally and psychologically.

Asking for a biography is fun. What did they do in their life? What was their profession? What jobs did they perform? How many children do they have? What are their hobbies? These answers may be obtained when a family member or a caregiver writes freely. It may be of interest to see how the resident-to-be communicates in writing, also. This process provides a sense of their values--a sense of where they were.

At the admission time--note the process of admission-but, the time when family members sign papers and bring personal belongings, the staff should not try to disseminate all needed information. Instead, family members should be encouraged to return within a two week period with detailed questions for either a staff member or a social worker.

Turmoil with institutionalization, relative to visitation responses, occurs during the admission process visits. The family arrives and they have been chatting with the patient--all of a sudden, the patient does not recognize them--they are devastated. The patient does not remember their names. This is the period when a staff member should intervene and remind them that this is part of the disease. The staff member should also be caring and willing to listen. The attendant should let them express how sad it is--the loss and guilt that they are experiencing. Shock exists at this stage, leading to devastation.

It is very helpful to introduce families to other Alzheimer's family member, because as they visit they may chat with each other. Furthermore, when they come to visit with the patients, their own family members cannot communication with them anymore. So, visiting becomes a very painful process. Families either wish to run, or they sit and feel very depressed because they cannot talk to their relative. But, they may find that this other family is there and they are experiencing the same thing. So the families can communicate with each other--support each other--and, help each other while they are with the victim who cannot communicate. The are present--that kind of presence makes them feel better. This supportive environment may also have a positive effect in reducing perception of burden and depression levels among family members.

Social Security Number_ _ _ _

UNDERSTANDING THE FAMILY'S BURDEN

Circle all the correct answers.

1. Alzheimer's disease:

   a) causes memory loss and changes judgment and personality of the resident.
   b) may cause disagreement among family members.
   c) Treat the family as having the disease also.
   d) Develop care plans which expands to the family

2. Among the stresses the family faces are:

   a) first, figuring out what is going on with the patient before entering the nursing home.
   b) denying it on the surface and the emotions involved with this.
   c) denial of the doctor's diagnosis.
   d) let the nursing home staff worry with dad.

3. When the relative is admitted as a resident, you as primary care should:

   a) listen but not pay too much attention to what family members think and say to you.
   b) listen and try not to change their mind and opinion, but let them talk it out with you.
   c) put up with the family and try to keep relationships open.
   d) confront the family directly and try to show them you know how to care for dad.

4. Family members tend to:

   a) carry their anger out on the caregiver.
   b) immediately accept the ways their lives will be changed-and-cooperate.
   c) feel guilty about not having done more for dad when he was well.
   d) grieve dad's illness and become fully cooperative with the nursing home staff.

5. When dad arrives at the nursing home as a resident, the family:

   a) grieve that they are abandoning dad.
   b) just turn him over to the nursing home staff hardly interfering.
   c) show their resentment toward nursing home staff.
   d) the children who have the greatest conflict are easiest for the nursing home staff to handle.

INSTRUCTOR'S GUIDE for SENSORY LOSS EXERCISE

ESTIMATED TIME: 90 minutes

DOMAIN: Sensory - Hearing and Vision Functioning

OBJECTIVES: The participant will be able to:

1. Define the following terms and distinguish among them.
   Cataract — Opacity of lens
   Unilateral — Bilateral
   Cerumen

2. Demonstrate ways to test for hearing or vision loss.

3. Demonstrate effective nursing intervention.

4. Discuss cause of hearing or vision loss.

5. List behavior traits symptomatic to sensory loss.

6. Describe physical change to the lens which occurs with aging.

7. Modify the environment to accommodate sensory loss.

EVALUATION CRITERIA

Without error, complete the questions in the Sensory Loss Exercise.

LEARNING RESOURCES

Primary

1. Study Guide

2. Gwyther, Lisa P. Care of Alzheimer's patients: A Manual for Nursing Home Staff, 1985.

3. Cote, Lucien "Aging of the Brain and Dementia," Principles of Neurol Science, 1981.

4. Mace, N. "Facets of Dementia", Journal of Gerontological Nursing, Vol. II no. 10, 1986.

5. Berg, Leonard "Does Alzheimer Disease Represent an Exaggeration of Normal Aging?", Arch Neurol Vol. 42 August 1985, 737-739.

6. Boone, Boyles and Koopmann "Communication Aspects of Aging", Otolaryngologic Clinics of North America, Vol. 15 no. 2, May 1982, 313-327.

7. Isbell, Lou and Lusk, Edith "The Disoriented Person in Your Life: Relating is their Therapy", Home Economics Guide, University of Missouri-Columbia, Sept, 1961.

8. Lyon, Glee Gamble "Stimulation Through Remotivation", American journal of nursing, 1971.

9. Morris, M. and Rhodes, M. "Guidelines for the Care of Confused Patients", American Journal of Nursing, Vol. 72 1630-1633.

KEY WORDS:

Lens	Non-verbal communication
Pupil	Gesture
Disorientation	Voice pitch

SENSORY LOSS

There are two senses which undergo drastic changes with advancing age. Consequently, these changes impact the ability to communicate with elderly residents. The first sense is that of vision and the second is hearing.

It seems you can pretty much determine that we know the world about us by the way we interact with it. We interact with our world primarily by what we see and what we hear. Many older residents have lost some of their abilities to hear and see well. If you took all the medical records from a particular facility and researched each one carefully, there would only be a few medical records that would tell how much functional vision or hearing residents have lost. These parameters are generally estimated. Usually, no documentation exists of how much functional vision and hearing residents have lost.

Vision Loss

Many vision changes occur with age. There are changes that occur in the eye itself that creates problems interpreting the environment. The changes are normal and if detected early may be deterred via corrective lenses or opthalmologic surgery.

The size of the pupil in the eye becomes smaller with aging. There is decreased reactivity to light in the pupil. The primary assessment of a resident is based upon how quickly the pupil of the eye gets small when exposed to light. A decrease in the elasticity of the lenses of the eye occurs also. Think of the lens of the camera as that big round thing that helps us focus. The lens of the eye is somewhat similar to the lens of the camera. Normally, the lens is very pliable and elastic but with aging it sometimes becomes rigid.

Age increases the thickness of the lens. When you walk, things appear cloudy. Complete cloudiness of a lens is apparent when cataracts exist. The lens gets yellow with age, altering the ability to discern colors. For example, if you presented a picture inclusive of blue and green coloration, an individual would see little because the colors would blend together. There is a decrease in the speed at which the cones' of the eye recover from adaptation to darkness. For example, when you take an older person in the bathroom and it is dark in there and you flip the light switch on, sometimes they get very frightened. They are fightened because they cannot see the environment once it is lighted as quickly as you or I can.

Let's consider some of the functional problems that each change presents for a caregiver. First of all, decrease in sensitivity to light--this is due in part to a decrease in pupil size. This decreased size limits the amount of light that can enter the eye. Decreased sensitivity is also compounded by the increased thickness of the lens. To the elderly person, this means that they are going to have regular difficulty going out at night. They will avoid going out at night. I suspect that some family members that have taken elderly people and returned them during the evening will attest that residents become agitated when they are returned at night. What is happening is that they cannot interpret the environment well when they come back at night.

Another problem with aging is an increased sensitivity to light. This is due to an increase in the opacity of the lens. The light that enters into the older eye becomes fused.

Altered color vision is rather fascinating. Many older people cannot watch color television. They do not like color television sets because they have difficulty interpreting the colors. The colors blue and green tend to merge together. They tend to like black and white television because they do not have to interpret the colors. Watching a colored set, however, causes intense eye strain which is sometimes compounded with headaches.

Cataracts are a common problem in older residents. Cataracts are present when the lens becomes almost completely ossified. Cataracts can be removed in older residents.

What symptoms are indicative of visual problems? Perhaps, if someone has a problem with coordination; i.e., an individual always misses the placement of a cup upon a saucer--this might indicate a vision problem. Furthermore, if a resident persistenly positions objects--they tell you I want the object right here--then this may signal visual defects. This behavior should not be interpreted as stubborness; but attributed to one's perception of field positioning. If you want an older person to use the urinal and you put it on the bedside table and their peripheral vision has been impared, the odds are that they are not going to be able to see it and will not remember it is there. Sometimes residents want objects directly in front of them so they can position them and remember their locations.

One of the signs of developing cataracts is that a person will begin to squint a lot. Residents do not know they are developing cataracts. Alteration in depth perception may indicate a visual problem. For example, someone goes to shake your hand and they over reach it--may indicate a visual problem

Some basic assessment strategies are available to the caregivers. You can ask the resident to tell the time on a medium sized (6" diameter) clock. If they can see the clock, then that should indicate if the person can see accurately to respond. We can also hold fingers up in front of the person's eye and ask them

if they can see the fingers. We can proceed to cover one eye and then the other, using various media to assess the visual accuracy of the eye in question.

The nurse attendant may administer more intense assessment procedures. The pupils should be checked individually how each responds to a light stimulus. The resident may be asked to read from a newspaper. Peripheral vision should be checked also. This is done by covering one eye and slowly moving the index finger up, down, and across the field of vision. The resident is asked to indicate each position. The second eye is examined accordingly. On the average the over-70 resident has lost almost thirty percent of the peripheral vision. With peripheral vision loss it is important to position objects where they can be seen and consistently in the same place.

The caregiver should observe where the resident wishes to have an object placed. This insintence is not stubborness, but reflects an area of recognition of functioning. Labeling objects boldly helps the poorly-sighted resident to function better.

Simplifying the visual field is also helpful. For example, the resident has trouble eating from his/her tray: place a plate down with one or two objects on it, as too many objects on the tray might confuse the person. The rest of the meal may be served later.

The glare from polished floorsmay be reduced. Highly-glossed floors present many problems for an elderly person due to the reflection of ceiling and other lights. This glare is dangerous because it prevents the resident from being able to look directly down and see feet and objects clearly.

Hearing Loss

Let us now consider hearing loss. Interestingly enough, almost everyone has experienced hearing loss at one point in their life. Hearing loss begins for everyone in their mid-twenties. Fifty-five percent of the persons who have functional hearing loss are over the age of sixty-five. The hearing problems that we have can be divided into three categories. The lack of an ability to detect the volume of sound is the first type. You cannot judge the loudness of something that you have heard. We know that different levels of intensity exist, but we cannot detect the nearness of the sound. The second problem is the lack of the ability to detect pitch. The pitch enters certain consonants that are in our alphabet, such s, sh, and f. So the high frequency sounds are lost by the older person. Also, hearing loss can be unilateral or bilateral, meaning that either one side or both are affected.

Sometimes, we find that they have an impaction of the cerumen (ear wax) which will cause hearing loss problems. We know that

hearing loss may have an even greater impact on an older person than the loss of vision. There is evidence that suggests a strong correlation between hearing loss and depression. The older person who cannot hear is prone to feelings of isolation, because hearing loss makes communication with others very exhausting, and may find it too difficult.

What are some of the clues in the environment that you can detect in terms of knowing whether a person has a hearing problem? One classic sign is when the person speaks loudly. Another sign is the positioning of the head and body. Some people are aware of their hearing loss, and will compensate by tilting their head or leaning forward to hear you better. A resident who asks for things to be repeated several times is a probable indicator of hearing loss. If you have said something which you think was spoken clearly, and you receive blank looks or looks of confusion, this may be attributed to a hearing problem. Sometimes an individual will find it too difficult to hear what is being said to them and will isolate themselves to avoid interacting with others. A marked decrease in the resident's attention span or social involvement may also indicate a hearing problem. If you work with someone who has a hearing defect, they will very often listen closely to the first couple things you say, but may give up if it is too difficult to understand you. Finally, another tell-tale symptom is emotional frustration. Most frustration occurs in the early stages of hearing loss. Many will not wish to accept the loss of their hearing, and will refuse to obtain or use a hearing aid.

Some of the assessment procedures available do not require a nursing education. If you have a watch that ticks, you can just put the watch by the person's head or ear and see if they can or cannot hear the ticking. We may also talk to the person while we are facing them and then continue to talk with the head turned away. Many older people have learned to lipread and they do not realize that they lipread.

What are some of the things that you can do for a person with a hearing problem? First of all, if he or she has a hearing aid it should be operative. Many people have hearing aids that do not work. Second, be sure that the resident knows that you are about to speak to her/him before you begin conversing. Do not come into the room with a stack of linen in your hands, start making the bed and start talking to Joe who is in the other bed, and expect Joe to know what you are talking about.

Gestures are also useful for individuals with a hearing problem. You can pick up objects that you are talking about to give then some frame of reference. Use short sentences when you talk to someone with a hearing loss--one subject one verb per sentence--one thought at a time. Also, if a person has asked you a question and it is a yes or no answer, but you want to provide more explanation, position the yes or no at the beginning of the sentence. Do not make the resident listen for a whole paragraph and then say no at the end. That is very frustrating. If you are

working with a resident with a hearing problem, you should avoid shouting. As soon as you shout, you have placed your statement further outside the individual's hearing range than if you were talking softly and lowering the pitch. So, if you are going to talk loudly, you are going to have to lower the pitch of your voice. Do not shout!

The attendant should be aware of his/her non-verbal communication. You cannot talk loudly and smile. You cannot even talk loudly and look pleasant. When you talk loudly you are either going to look angry or frustrated. The message you send when you are talking loudly is that you are frustrated or may even be angry; i.e. "I do not particularly want to be here." Some research has indicated that facial muscles send messages to the brain to dictate how we feel. If we are working with someone who is is hard of hearing and we do not look pleasant, the non-verbal message is, "We do not want to be here." When we work with people witn a hearing loss, we have to make a conscious effort to compensate for that. We have to slow down the rate we speak first of all. Above all else, indicate that you are glad to be taking care of that person. You also want to send your brain the message that the task is enjoyable.

SENSORY LOSS STUDY GUIDE

....HEARING

NURSING DIAGNOSIS

Behavior or symptom in an elderly person that could be indicative of a hearing problem:

Speaks with a loud voice.

Tilts head or leans forward when listening.

Asks to have a sentence repeated several times.

Gives a blank look even when you think you have spoken clearly.

Isolates his or herself from others.

Short attention span.

Emotional frustration (usually occurs in early stages of hearing loss).

Assessment procedures for judging hearing loss:

Place a watch that ticks by the person's ear.

Talk to the resident when facing him/her, then continue talking when not facing the resident, and observe the behavior.

NURSING INTERVENTIONS

Make sure hearing aid is operating and properly adjusted.

Check ears for impacted cerumen.

Get person's attention before speaking with them. Touch them a safe part of the body, then pause and wait for a response.

Use gestures effectively, show person the object to give them a frame of reference.

Place the 'yes' or 'no' part of a response at the beginning.

Avoid shouting, if you talk loudly, lower pitch of your voice.

Speak slower. Stop and smile between sentences.

Indicate your willingness to care for the person.

SENSORY LOSS

....Vision

NURSING DIAGNOSIS

Behavior or symptom in an elderly person that could be indicative of a vision problem:

Person says things appear cloudy.

Person is frightened when brought from light to dark room or situation.

Have difficulty, or avoid, going out at night.

Person is agitated when they return at night.

Doesn't like to go out in the winter.

Can't see snow and ice.

Glare is too strong (happens at lakes or the seashore too)

Person does not want to watch television, especially color tv

Person gets headaches while watching television.

Person appears uncoordinated i.e. misses suacer when setting cup down.

Person always places objects in a certain spot, or insists you do so.

Person begins to squint a lot.

NURSING INTERVENTIONS

Ask the person to tell the time on a medium sized clock.

Hold up your fingers.

Cover one eye at a time, have him or her identify different objects.

Check the pupils to see if they respond equally to light.

Have the person follow your fingers up, down, and across.

Check the person's peripheral vision.

If the person is literate, ask them to read the newspaper to you.

Position object in the same place or where he or she tell you to place them.

Put the person's name or a picture of him or her on the door to the room.

When eating, give the person one or two items of food at a time.

Before moving a person, tell the person face-to-face that you are going to move them and where you are taking them.

Reduce glare in the person's environment.

SENSORY LOSS

PLEASE ANSWER THE FOLLOWING QUESTIONS. The answers to the questions are contained in the paragraphs preceeding. Remember, there may be more than one correct answer to each question. Circle all the correct answers.

1. What vision-related changes occur with most elderly people?

   a) The size of the pupil becomes smaller causing a decrease in in sensitivity to light.
   b) The size of the pupil becomes smaller increasing the intensity of light entering the eye.
   c) The thickness of the lens of the eye is reduced causing a decrease in sensitivity to light.'
   d) The thickness of the lens of the eye is increased causing a decrease in sensitivity to light.

2. A resident's records usually indicate how much functional vision and functional hearing she or he has lost.
   TRUE FALSE

3. If an elderly person has problems with color vison, the best type of television for that person would be a high contrast color model.
   TRUE FALSE

4. List four ways of making it easier for a hearing impaired person to understand you.

a) _____

b) _____

c) _____

d) _____

5. List four ways you can help a person with vison problems.

a) _____

b) _____

c) _____

d) _____

SENSORY LOSS EXERCISE

PLEASE ANSWER THE FOLLOWING QUESTIONS. The answers to the questions are contained in the paragraphs proceding. Remember, there may be more than one correct answer to each question. Circle all the correct answers.

1. What vision related changes occur with most elderly people?

   a) The size of the pupil becomes smaller causing a decrease in sensitivity to light.
   b) The size of the pupil becomes smaller increasing the intensity of light entering the eye.
   c) The thickness of the lens of the eye is reduced causing a decrease in sensitivity to light.
   d) The thickness of the lens of the eye is increased causing a decrease in sensitivity to light.

2. A resident's records usually indicate how much functional vision and functional hearing she or he has lost.
   TRUE FALSE

3. If an elderly person has problems with color vision, the best type of television for that person to watch would be a high contrast color model.
   TRUE FALSE

4. List four ways of making it easier for a hearing impaired person to understand you.

   a) _____

   b) _____

   c) _____

   d) _____

5. List four ways you can help a person with vision problems.

   a) _____

   b) _____

   c) _____

   d) _____

6. Whish of the following are possible signs of hearing loss?

   a) the person is frightened when brought from a light to a dark room or situation.

   b) the person repeats the same sentence time after time.

   c) the person appears to have a short attention span.

   d) the person isolates his or herself from others.

7. To assess whether a person has a hearing loss you could...

   a) ask them to read a newspaper (if you know they are literate).

   b) ask the person a clear simple question when you are not facing them.

   c) hold up your fingers

   d) place a watch that ticks by his or her ear.

INSTRUCTOR'S GUIDE FOR DEATH AND BEREAVEMENT EXERCISE

ESTIMATED TIME: 90 minutes

DOMAIN: Affective Domain

OBJECTIVE: At the conclusiion of this training, the participant will be able to:

1. Define the following terms and distinguish between them

Anger	Bargaining	Depression
Denial	Grief	Acceptance

2. List a minimum of four nursing strategies for relating to the dying resident.

3. Discuss each stage of dying and distinguish differences.

EVALUATION CRITERIA

Without error, complete the Death and Bereavement Exercise

LEARNING RESOURCES

Primary

1. Study Guide

2. Dyck, Arthur J. "Ethical Aspects of Care for the Dying Incompetent," Journal of the American Geriatrics Society, Vol. 32 no. 9, September, 1984, pp. 661-664.

3. Scott, J.P. "Families of Alzheimers's Victims. Family Support to the Caregivers." Journal of the American Geriatrics Society, Vol. 34 no. 5, May, 1986, pp. 348-354.

4. Chandra, V., "Conditions Associated with Alzheimer's Disease: A Care-Control Study," Neurology, Vol. 36 no. 2, February, 1986, pp. 209-211.

5. Ridder, M., "Nursing Update on Alzheimer's Disease," Journal of Neurosurgical Nursing, Vol. 17 no. 3, June 1985, pp. 190-200.

6. Mittler, M.M., "When People Die. Cause of Death Versus Time of Death," American Journal of Medicine, Vol. 82 no. 2, February, 1987, pp. 266-274.

7. Tolle, S.W., "How to Manage Patient Death and Care for the Bereaved," Postgraduate Medicine, Vol. 78 no. 2, August, 1985, pp. 87-89.

8. Gwyther, Lisa P. "Care for Caregivers," Journal of Gerontological Nursing, Vol. 9 no. 2, February, 1983, pp. 93-95.

9. Gwyther, Lisa P. Care of Alzheimer's Patients: A Memorial for Nursing Home Staff, 1985.

DYING AND BEREAVEMENT

Understanding the death process is requisite when one has associations with terminally ill patients. In a general setting, most of us go about our own lives in our own way, thinking everybody is going to die but us. How many of you have really thought that you were going to die? Have you really given that any thougnt at all? Most of us don't, until it becomes apparent in our own lives. Now, I am going to throw out a thought for you because it will bring us closer together. The thought is--in your own mind, think of someone you love the most that has died. How would you respond to that situation? If you have not had that experience, I promise you--you will. Usually, an experience of this caliber enables you to get in touch with the death process.

Most of us consider ourselves to be healthy. Actually, healthy only means that this morning we were able to rise and go to work. Maybe something hurt; but, we were determined to maintain our commitment. Some mornings, we get up and wonder if we are going to show up for work. We know the consequences of our actions. When our world, however, is interrupted, we become scared. How many of you have ever been hospitalized? Were you afraid? Were you afraid of the unknown?

I see death as very beautiful because it sets limits for us. Most terminally ill patients have six months or less to live. The time period differs with the Alzheimer's patient.. I am presently building a scenario, because I want you to think about the bereaved stages.

We progress from a healthy stage into other stages. Now, I am going to label these stages for you and it's going to look like there is a progression--there really isn't. An individual was healthy--what ever that means. S/he was able to function and didn't know anything was wrong with her/him. S/he went for a check-up, found s/he had some problems--found s/he had inoperable cancer and would die in six months. Her/his world was interrupted. This is what I want you to think about with the family of a demented individual--the Alzheimer's patient. We will assess the need and we will tend to those needs probably on a daily basis. But, the process is different for both the family and the dying person. We will assess the needs of the Alzheimer's patient as s/he deteriorates.

The first stage is the denial stage. I want to make this more personable, because, we have each experienced an aspect of this stage. Has anything traumatic occurred in your life?--Has anything hurt you to the point that you were devastated? Maybe, it was a bad love affair. How many of you have ever been in love? All you need to do is be divorced or have someone ultimately reject you. Even though we have our own defensive mechanisms and our own coping techniques--our initial responses are generally quite similar--we will say I'm the

better person--he/she could not say they don't want me. I'll dump him or her. They will have to leave.

Usually, we tend to bottle our emotions and avoid articulation of our inner feelings. But, we each have our own emotional mechanisms--even in the death process. The first stage is that of denial--families consult other doctors--why? One response has been--that guy has always been a quack, I'll get a second opinion. Usually, one hopes that the new doctor will say everything is okay, and the other diagnoses were mistakes. If the initial diagnosis was not a mistake, then perhaps there was a problem with lab tests--the biopsy may have been wrong--somebody could have misinterpreted the results. These guys want to desperately return to the healthy state.

Anger is the second stage; but, this emotion is the one with which a lot of people, particularly real religious people, have problems. Who do we get mad at? When things are the worst, who's fault is it? Is it God's? God does everything. It is easy to blame God, but why? Maybe, because God will love us regardless of what we do. God wanted this to happen. Being angry is such a normal reaction and patients feel they are being cheated out of life's greater pleasures. Their only recourse seems to be the direction of their anger toward God.

Where are caregivers placed in this emotional process? You have to understand that caregivers do not intend to make others the target of their frustrations. Maybe they do tempestuous, mean things but they do not really intend to abuse anyone. They are projecting their frustrations--their anger--because, they have lost a loved one to this dementing illness, and unfortunately others become the mechanism through which they release their emotions.

The third stage of grief is bargaining. Have any of you ever bargained for anything? Patients often bargain for time. Have you ever seen someone dying--actively dying and you think they can't continue living? But, you look and they are still alive. There is no clinical reason why that person should be alive--but they just won't die. If they have unfinisned business to do--and maybe we will never know what that was or is, but if they have unfinished business--I promise you they will do that unfinished business.

Have you ever seen someone trying to die and they have a child or someone really close in their life in California or somewhere--and they had to wait until that child comes home before they die? Have any of you had that experience? Sure, it happens all the time. The "if I could only do this" becomes prevalent. We bargain all the time, but it doesn't always come into our consciousness.

The fourth stage of grief is preparatory depression. What is preparatory depression? What happens when all else is done? What do you see? How do you picture it? Do you have a picture in your mind? Often times this is the time you see the patient lay their head back on the pillow. They are very much in touch with what is going on--maybe you don't believe that--sometimes we call that

comatose--sometimes we call it sleep. The stage is preparatory depression. At this point and time when the patient has resolved themselves to death--they are tired--they just want to die. They are ready to have a little peace. They have closed the book--the bookkeeping is complete. Sometimes, they just cannot die, because within themselves, there is still some conflict--depression comes.

Remember that when a patient, friend, or someone in your family dies they leave everyone. We, however, only lose one person. Except, in extreme cases where multiple deaths occur. Have you ever thought about that? Do you realize how many good-byes there are to say? Think about your own world and people that are important to you in that world. Do you realize how many good-byes you have?

Acceptance is the fifth and final stage of the grief process. Some people often ask if religious people accept death differently? I think the answer to that is yes.

We've now analyzed the stages of grief. The stages appear as if they were progressive--however, you need to understand that there is no graduation date from this disease. Many patients approach the denial stage and deny their sickness--they can't force themselves to accept their diagnosis. They need that denial. And, as caregiver, the important thing that we must do is respect them and their contentions.

The medical profession can become too familiar with the concepts of death. Many professionals strive to have a patient accept dying. One initially places a patient in the denial stage. Suddenly s/he throws something to the floor, or maybe s/he dropped something on the floor; but, one perceives that s/he threw it to the floor--s/he's angry and must be in the anger stage is the common assessment. Pretty soon, a professional has placed the patient in the acceptance stage without the patient's knowledge. We have to be really careful because it's like the old addict--too much information is dangerous. We must always look--we must learn to look--maybe not label, but look where people are, relative to a specific stage. We then, should have respect for this individual and do not force him/her through the various stages. We have to recognize where they are and respect that.

Let's talk about the Alzheimer's patient--the Alzheimer's family--the cargivers. Working in a convalescence home can be disheartening. Most nursing home workers have had some unpleasant experiences with patients and even worst, with the patient's family. They don't understand the allowances made in these stages.

Have any of you awakened, sluggishly; but, went to work even after having had a fight with your spouse, or experiencing something unpleasant before you ever go there? Maybe, you were crying when you arrived at work. So, what happens when we get to work?--Usually, we take it out on everybody else.

We're now at work after fighting. As usual, we have our normal responsibilities; but, on this day--we have eight patients instead of

six. How are we going to perform the short cuts needed to accomplish our tasks? To complicate matters, the head nurse has had a rotten night. Furthermore, the administrator comes in and s/he's out of money; so, sh/he needs to reduce the budget. How do we react to these situations? How do we relate to the people with whom we are working? Do we say hi, I'm having a good day; are you?--Sometimes, we get angry and frustrated.

These are common reactions. We need to possess an awareness for others' needs. Let us think about whom we are and what makes us happy. What makes us mad? Why do we respond to situations the way we do? Specifically, why do we choose to respond to death as we do? We have had neighbors and friends die--we also experienced the deaths of celebrities. Normally, we'll respond isn't that a shame "so and so" died; but, we tend not to personalize death until we actually experience a death of a relative or close friend.

We, however, need to understand that we need to take full advantage of all situations we confront. Have you ever reminisced saying if I had to do it all over again I'd do this, this, and this? Chances are you wouldn't; because, when you look back you have more information.

Through death education, I have come to understand that it is okay to cry. It is okay to love patients. It is okay to touch. Touch is really all we have when we run out of things to say. When they enter preparatory depression there is nothing left to say. You have said it all. They have said their good-byes. You have said you good-byes. There is nothing left to say. Touch becomes our last resort.

We are born in a world of touch. What happens when you are born? What is the first thing that happens? Somebody touches you. Someone separates you from your umbilical attachment--they spank you--they wash you--they dress you. We spend all this money on being born, only to die at a later time. There are some regulations. Normally, there has to be a delivery room nurse, a nurse operating the nursery, and three registered nurses. But when people die, who is assigned to the dying patient? Have you ever considered how many people die alone? Most people aren't afraid of dying--they are afraid of dying alone. As lonely as death is and as much as we know someone is there, many medical professionals pray that the patient is dead by the time that they arrive, so that they can avoid watching the family go through the long term pain.

The stages are approached differently when death is considered at the personal level. Dying should be a personal matter. Some consider the care of dying patients as awful. Caring for these patients, however, can be the most rewarding and beautiful work in the world because the patients have a sense of how much longer they will live. The families also know that they have limited time with the patient, and they spend that time with quality.

How about the caregivers? In a nursing home setting, you become acquainted with patients on a first name basis. There are those that you really love and there are those that you hate. And, that's okay. We don't have to love everybody. We have to treat everybody with respect and dignity, but it is okay not to like everybody. Now, some folks cannot deal with that. How many of you like yourself? How many of you think you are pretty neat people? Some of you probably cannot admit your personal feelings, but if I were to whisper the question into your ear, you would probably respond in the affirmative.

I want you to walk up to the mirror and look at yourself--really look at yourself--some of you won't recognize the person you see. I want you to spend a few minutes--I want you to think about what you are doing with your life right now. Are you happy? Are you unhappy? If you are either of those, and hopefully you are; what places you in that situation? Why are you happy? If you can look in the mirror and be honest with your self, then you will reach the level of happiness--at least mentally. If you are not satisfied, then you have qualities that bother you, not other people. You cannot be responsbile for what other people think. We have no right to our expectations on other people. But, we should love ourselves because if we don't, that effects everybody you know.

The families of demented patients possess similar qualities of concern and responsibility. When one is dying, it doesn't really matter how much money one has--the status of one's life--the color of one's skin--one's age--nothing matters. The quality of life is most important. How do we live it? Who are we? What controls our world? Who are the people in our world? The beauty of taking care of a terminal patient is the time limitations.

The underlying message comes from the terminal patient who has learned to live through the dying process. The message is always the same. If I could go back, how would I spend my time. I would have done this. I would have done that. If I could only go back. The beauty for most of us is that we are healthy and remain blessed with opportunities. We can continue to observe our mirrored images and make changes, accordingly.

The people who consider their lives to have approached a stop because of their age are unlucky--because many opportunities remain for each one of us. There are ways--if you find your master plan--to just grab on to life. We have the intelligence to reach out and attain this process.

We have done many things in the traditional mode of care, relative to taking care of the dying. We justify most our actions. Yet it remains in human--pagan--to let people die alone.

We are all pretty much alike. You strip us down and take us apart and we are all designed in a similar manner. We are also similar in our experiences--We are all born to die at some appointed time. We have nothing to lose--we are going to die anyway. We all

depart life through the same medium of death. The person underneath makes the difference.

First, we have to assess our true identities. We need to rationalize our actions. If I were that person and if my mother or father were dying of Alzheimer's, how would I feel? How would I relate? How could I relate and treat them with the compassion they deserve? It's tough--it's a tough job. We could look and say well, I am healthy but, my mom and my dad are not. Would I deny it? Would I be angry? Would I criticize the medical team and say why did you let my mother wander away? How would I act? Maybe and only then can we understand--we can related to them in a humane kind of way. It is tough--we have tough jobs.

We sometimes do stupid things in the name of what we believe is right--but, that is only because we don't know how to deal with dementia. As we consider sharing with the patient and sharing with the family, we can acquire many advantages. We, however, are unable to acquire these advantages until we asses where we are and where we are going.

I've talked about dying, but you have to understand that these families die every second of the way with these people. Do any of you know how hard it would be to sit and watch someone you love deteriorate and die? We generally cannot provide assistance to these individuals, unless we are able to cope with ourselves.

There is one point that I want to make very quickly--I think a nursing home facility provides a closer type of care, because the family involvement is much more so than in a hospital. The difference in the care that we use in a nursing home and hospice program is that it isn't just the patient that goes in for care but the family--patient and family represent the unit of care. Who are caregivers? I our family circle of care--demonstrated as a wheel--no one is more important than anybody else.

In the wheel structure, the family may relate much better to the volunteer, or the clergy, or nursing assistant, or to the social worker. The laundry person is often closer to the patient, because the patients don't feel threatened. This is what we call a care wheel.

This is the most important function that you serve--the family. Do not just consider the patient, but think about that family--what is there in the behavior of that family that you can change for the better even if they are hateful and mean to you. Stop and just think--I wonder how I would feel if that were my mom or my dad? And sometimes you have to understand that there are just some mean people I have ever worked with--they just cannot get beyond themselves. Sometimes you just have to give them time to figure out who they are and where they are at. Knowing this, will enable death and bereavement to be approached in a more intellectual, yet caring manner.

STAGES OF GRIEF

DENIAL

When faced with a diagnosis and short prognosis with terminal illness, the patient's first inclination may be to deny or disbelieve this horrible tragedy that is happening. The clinical picture often reflects behavior of running from one doctor to another in an effort to refute the positive findings. The human feeling often experienced is a combination of confusion, sadness, overwhelming fear and disbelief. Many patients die in the denial stage and their choice must be respected. We must not push our own values and our own personal needs for their acceptance of the death.

ANGER

This is a stage that is difficult for family and caregivers to relate to. The patient and family cannot understand why this outrageous situation has come into their lives. The question "WHY ME?" is so overwhelming that the patient often manifests their frustrations in unacceptable ways. The favorite person to blame in this stage is God (or the God that the patient perceives as a superior being). Caregivers must understand that this is normal behavior and God is big enough to understand the patient's fear of death and will not retaliate. The patient and family should be allowed to be angry and act their anger out in a way that gives them relief. When a patient dies, they lose everyone. Those who are left lose only one, and anger often allows the relief that will lead to closure.

BARGAINING

Most of us bargain during our life, so to bargain at death is not unusual. Many times, the patient will bargain with God, particularly for a little more time. It is interesting to note that if the patient has unfinished business that is really important to them, i.e., a child being married or a child coming home to see them for the last time, the patient will be able to wait for this little bit of time and them be able to die. Another good example is when a spouse is dying. He or she will hold on until the mate tells them, in some way, that is O.K. for them to leave. Then the patient can die and usually does so in a peaceful climate.

PREPARATORY DEPRESSION

At this time, when everything has been said and the patient, family, and significant others are tired of the dying process and want it to be over, the patient is usually very quiet, withdrawn, and preoccupied with self. It is not unusual, clinically, to observe them lying back, eyes closed, tears, and seemingly alone. Many times, it is a sad time because the patient doesn't die, but the whole situation continues for

a period of time. There are feelings of quiet hostility, guilt, and no need to repeat the good byes. The patient, after a while, may seem to perk up. This usually occurs jsut before death and the people involved in tnis vigil may even regain some false hope. Often times, after a brief period, the patient will die and the family is left with their confusion and the long-awaited death appears to be sudden. Even though everyone has been prepared for and expected the death, at the time of death they are not ready to accept it. The clinical picture is usually one of the patient lying quietly, sad and tearful, with an awareness that he or she will soon move to another place.

ACCEPTANCE

This is the beautiful stage in that, many times, it occurs when the patient feels that he or she has lived a full life and doesn't seem cheated out of time. This stage is no respecter of age. An example of this stage might be a person who has spent most of their life in a close religious sense. The dying process seems to be easier and more acceptable in a patient who has had a close relationship with their God. whoever that might be. Family and caregivers must be especially careful not to force their own religious values or beliefs on a very vulnerable patient and family.

DEATH & BEREAVEMENT EXERCISE

PLEASE ANSWER THE FOLLOWING QUESTIONS. The answers to the questions are contained in the paragraphs proceeding. Remember, there may be more than one correct answer to each question. Circle all the correct answers.

1. Which of the following are examples of 'denial'?

   a) Believing and accepting the family doctor's diagnosis.

   b) "My mother has never been sick before, I'm sure there is a mistake.

   c) "I'm going to take my husband to another doctor for a 'second opinion'."

   d) "We need to have the doctor re-do the lab tests."

2. The stages of grief in their proper order are:

   a) Anger, hope, bargaining, forgiveness, depression.

   b) Denial, anger, bargaining, preparatory depression, acceptance.

   c) Denial, forgiveness, hope, acceptance, anger.

   d) Depression, bargaining, anger, preparatory depression, forgiveness.

3. The final stage of grief is:

   a) A terrible stage if the patient feels he or she has lived a full life.

   b) A time when family and caregivers should be careful not to force their own religious values onto the patient or his or her family.

   c) Easier for people with strong religious beliefs.

   d) A time for family and caregivers to talk about believing and trusting in God.

4. People who work with terminally ill patients and their families should be careful not to

a) Label a patient as being in a certain stage without a thorough evaluation.

b) Talk about death or dying around patients and their families.

c) Listen too closely to the patient.

d) Let too much information become dangerous.

5. A lesson to be learned from 'Dying and Bereavement' is

a) It is best to hold our emotions inside and not talk about our problems.

b) That anything traumatic in your life can bring about one or more of the stages of grief.

c) An event such as a divorce or a rejection from a friend is not related to the 5 stages of grief.

d) Our defense mechanisms protect us from emotional pain. The 5 stages are necessary, but you need to be aware of them.

6. It is important to

a) Have an awareness for other's needs.

b) Never cry in front of others.

c) Not become involved with residents.

d) Remember that most people are afraid of dying alone, not of dying.

7. We tend not to personalize death until we experience the death of a relative or close friend.

TRUE FALSE

8. We have to love everybody even if we don't treat them with respect.

TRUE FALSE